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CONCEPTUALIZING SPIRITUAL CARE IN THREE DIVERSE HOSPICES: A PHENOMENOLOGICAL STUDY

by

Diana S. Batten

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Social Welfare. The City University of New York.

1997

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This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare.

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Abstract

CONCEPTUALIZING SPIRITUAL CARE IN THREE DIVERSE HOSPICES: A PHENOMENOLOGICAL STUDY

by

Diana S. Batten

Advisor: Professor Irwin Epstein

Recent efforts to reintegrate religion and spirituality within social work have been hampered by the absence of empirically grounded conceptual frameworks for its incorporation into education and practice. Nonetheless, studies have documented the linkage between religion/spirituality and terminal illness. Hospice, where spiritual care is incorporated into holistic health care, draws upon this linkage.

This qualitative study, utilizing phenomenological methodology, seeks to describe and conceptualize how spiritual care is rendered in three hospices by identifying its meanings and practices. In addition to agency observation and review of agency documents. interviews were conducted with staff and volunteers who identified themselves as spiritual care providers in the hospices which serve clients with predominantly either Roman Catholic, Protestant or Jewish religious affiliations.

Grounded theory methodology was utilized in a cross-case content analysis of the interviews. Individual and organizational meanings and practices of spiritual care emerged

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from this analysis. An analysis of the practices, utilizing a matrix of psychospiritual care. yielded a spiritual care process with identifiable phases and foci of activity.

Cross-agency analysis of these meanings and practices revealed major differences in the level of diversity in worker and client religious, spiritual orientations; and in the agencies' spiritual care cultures. Striking similarities were evident, however, in the use by workers and clients of religion and/or spirituality as a coping resource; and in the dynamics of the spiritual care process. A single conceptualization of spiritual care emerged, uniting its constituent elements.

Implications of this study for the integration of religion and spirituality within social work education, practice and research were discussed.

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Acknowledgements

The focus of this dissertation is the integration of religion and spirituality within social work, exemplified by the provision of spiritual care to terminally ill people in hospice. I have been privileged to know people who taught me about the strength of the human spirit. My clients, who displayed a strong spirit in the midst of "the darkness," have been some of my greatest teachers. I remember parents of newly diagnosed developmentally disabled children who somehow integrated the pain and suffering into their lives and continued to function. Mentally retarded adults taught me about courage when they chose to leave the security of an institution to live in the community where they were subject to ridicule and harassment. I recall Betty Jean, one of these people, who developed her funeral service in preparation for her death at 35 years of age.

I am deeply grateful to the staff, volunteers and administrators in the hospice agencies who provided the substance of this study. These spiritual care providers stand with open hands and open arms at the bedside of vulnerable, dying people. They are not only competent; they are compassionate. The poignant "stories" about their patients and families will always be with me. I trust that this document accurately reflects their words and conveys the profoundly meaningful service which they provide.

The faculty in the doctoral program consistently encouraged and supported my interest in the integration of religion and spirituality within social work. Paul Kurzman and Gary Anderson provided valuable suggestions for strengthening this document. I especially appreciate their excitement about the subject which they shared with me. Irwin Epstein

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helped me determine the focus of this work. He provided leadership and guidance with a healthy dose of humor. He was also a "nudge" periodically when I needed it. I am most grateful to Irwin for his steadfast support and understanding when I was experiencing "dark times" in my own life.

I am grateful to George Ziskind who formatted this document. The result is not only accurate, it also is visually pleasing, thanks to his keen eye for detail and aesthetics.

I could not have accomplished this work without the active support of my husband, Jim. He sacrificed many evenings and days, becoming a single parent during my "writing retreats." Writing a dissertation is a lonely task. Jim was my cheerleader and my partner in this endeavor. More than anything else, it was his absolute confidence in my ability which helped me persevere in this task. My son Todd "lost Mom" to child care providers over the years. He adapted marvelously to the changes and took the opportunity to make new friends.

Mary Riedy, my spiritual director, has helped reawaken my own spirituality which has sustained me in the last few months. Finally, I acknowledge my parents who gave me a strong foundation of social, moral and religious values which lead me to social work. My mother suffers from a degenerative disease, but her spirit remains strong. She is my role model of a person who faces death with hope.

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Chapter 1: Introduction

History

The ambivalent relationship between religion and social work is a fascinating component in the rich history of this profession. Initially guided by religious values and beliefs, social workers later repudiated religion as they endeavored to develop a professional standing. For the next 50 years, religion was made invisible in schools of social work and it remained latent in professional practice. Reintegrating religion and spirituality, its broader counterpart, within the profession has been the focus of renewed attention for the past 15 to 20 years.

The history of hospice, which offers palliative care to the terminally ill, reveals a similar, uneasy relationship with religion. When first established in England, this holistic approach to health care revolved around the religious, spiritual concerns of the patient. However, spiritual care was deemphasized in America in order to gain acceptance within the health care system. After 20 years of dormancy, hospice has refocused its attention on this component of care within the past two years.

Social Work

The social work profession's historical roots in religious beliefs and organizations is well documented (Spencer, 1957; Krill, 1969; Lieby, 1977 & 1985; Marty, 1980; Faver, 1986

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& 1987). The literature also reflects conflicts between social work and religion and the profession's purposeful move away from these roots (Spencer, 1956 & 1957; Stroup, 1962; Salomon, 1967; Imre, 1984; Joseph, 1987). Scholars have explained this separation, pointing to the rise of scientific empiricism and positivism (Spencer, 1956; Salomon, 1967) and conflicts between social work values and certain religious values and practices (Biestek, 1956; Constable, 1983). It is important to note that during the conflict between science and religion in the Post-Civil War era, there was also a migration away from social work by clergy particularly within evangelical Protestantism. "For these intense partisans, the only true alternatives were godly versus godless social service" (Marty, 1980, p. 465).

A general consensus has developed within the profession that all people have a world view, or a cognitive perception that places their life experiences in some context of meaning. For many, this world view includes a belief system with religious or spiritual elements. The tendency for people to emphasize or struggle with religious, spiritual issues at certain stages in their life course is well documented (Joseph, 1987 & 1988; Faver, 1989; Kilpatrick & Holland, 1990). The literature also demonstrates the importance of religion and spirituality among ethnic, cultural groups (Keefe, 1975; Delgado, 1977; Brandon, 1979; Cataldo, 1979; Delgado & Humm-Delgado, 1982; Canda, 1983; Laird, 1984). In spite of this consensus, the profession has maintained its distance from this aspect of human behavior and functioning.

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A renewed interest in religious and spiritual issues was first evident in the literature in the 1950's and has blossomed in the past fifteen years. At first, tentatively proposing that religion has a place in social work, (Spencer, 1961), educators and practitioners have progressively expressed concern about the separation between the two. Pointing to the rising interest and participation in religious activities in society, writers warn against the danger of not addressing clients' religious, spiritual needs and concerns (Keith-Lucas, 1958; Jaffe, 1961; Siporin, 1985; Faver, 1986a; Joseph, 1987; Canda, 1988a & 1988b; Logan, 1990; Kilpatrick & Holland, 1990; Dudley & Helfgott, 1990). Imre, (1971), Judah (1985) and Netting et. al. (1990) note that refraining from spiritual issues in practice does not guarantee that the worker's beliefs are not imposed on the client. Just as important are the implications for social work education. If the profession is to address clients' spiritual needs, students must acquire sufficient knowledge and skills (Imre, 1971; Judah, 1985; Netting et. al., 1990). The educational content should be presented in a manner which provides guidelines for appropriate usage (Spencer, 1961; Faver, 1987; Canda, 1989). Finally, if social work is to take religion and spirituality seriously, it will influence "our ways of knowing" (Faver, 1986b, p.27). Means of developing knowledge and research methods must include qualitative as well as quantitative approaches to studying human behavior and functioning (Stroup, 1962; Saloman, 1967; Watson, 1979; Imre, 1984; Siporin, 1985; Faver, 1986b).

In an effort to address these concerns, social work scholars and practitioners have struggled with meaningful definitions of "religion" and "spirituality" and have attempted

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to develop theoretical frameworks for the incorporation of spirituality into practice, education and research. The literature reveals progressively broader definitions for the terms "religion" and "spirituality" which account for diverse spiritual perspectives (Bisno, 1952; Spencer, 1957 & 1961; Keith-Lucas, 1960; Sinsheimer, 1969; Rizzuto, 1982; Siporin, 1985; Faver, 1986a; Canda, 1988; Logan, 1990; Constable, 1990; O'Brien, 1992). Studies reveal the wide variation in practitioners' religious/spiritual backgrounds and varying attitudes toward religion and spirituality in practice (Jaffe, 1961; Joseph, 1987; Sheridan et. al., 1990). Krill (1966), McLeod and Meyer (1967), Imre (1971), Faver (1986a) and Diblazio (1993) explore how a social worker's personal philosophy influences her practice. Several scholars propose models for incorporating spirituality within social work practice and education (Faver, 1986a; Joseph, 1987; Kilpatrick & Holland, 1990; Dudley and Helfgott, 1990; Netting et. al., 1990).

These attempts to develop frameworks for the inclusion of spirituality within the profession have been hampered by the absence of an agreed upon conceptual frame of reference. Lacking one professional frame of reference, Jaffe (1961) found that practitioners bring a series of personal frames of reference to their practice. Joseph (1987) and Canda (1989) emphasize the need for a conceptual scheme to assess religious issues and a systematic body of knowledge and skills to teach. All of these writers refer to the difficulty in finding definitions of terms acceptable to all social workers.

Hospice

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Hospice presents a setting where the spiritual dimension of service is addressed directly. A program which offers palliative health care for people in the final phase of terminal illness, hospice emphasizes treatment of the whole person by an interdisciplinary team which addresses the medical, psychological and **spiritual** needs of the patient and family. Hospice was first established in 1947 in England by Dame Cicely Saunders who was deeply moved during World War II by the ability of some people to endure unavoidable suffering and sustain meaning in their lives. A strong Christian, she compared the spiritual role of caregivers to the disciples of Christ in the garden of Gethsemane: "To stay with him, be there. In the case of hospice, **it's the patient's time. We should be there for the patient but not to tell him what to do"** [author's emphasis] (Wald, 1989, p.41). From its inception, St. Christopher's Hospice in London was viewed as a "pastoral community...with an interfaith, Christian foundation" (p.41).

The movement toward palliative and humanistic care in America coincided with the civil rights movement and the Viet Nam protests. Its inspiration arose out of what concerned caregivers most - patients' rights. By the mid-sixties, the psychosomatic nature of illness became credible, and holistic medicine emerged. Focusing on the patient as a whole person, medical, nursing, psychiatric and religious professionals came together, lowering barriers between Catholics, Protestants, Jews and humanists. In that atmosphere society was receptive, calling for services for the terminally ill. Beginning in 1974, hospices were established in hospitals, home care agencies and as free-standing organizations, becoming a counterforce in the health care system. Contrary to England where the spiritual aspect of

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]care was a primary focus, hospice leaders in America, a more pluraliastic society, did not emphasize this aspect, fearing it would jeopardize acceptance by the medical community. Despite this history, the American hospice movement maintains "the spiritual" in its paradigm.

The spiritual component of care presents special problems for hospice. As recently as 1988, O'Connor stated that, "The role of spiritual care in the American hospice persists as a subject of conjecture" (p.31). The word "spiritual " becomes even more elusive when a broad interpretation of the term goes beyond traditional religious beliefs and "...attempts to explain a dimension of health care provided by a variety of professional disciplines" (p.32). The hospice literature distinguishes between religion and spirituality and views the latter as the broader term which can encompass but does not always include the former (Wald, 1989; Millison & Dudley, 1990; Mount, 1993). The International Work Group on Death, Dying and Bereavement (1990) has developed a statement of principles regarding the provision of spiritual care. Hay (1989) has developed a spiritual assesment which endeavors to operationally define catagories of spiritual suffering.

Despite these efforts, no agreed upon conceptual frame of reference exists for the provision of spiritual care. Consequently, the implementation of spiritual care has been left largely to the individual hospice.

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Purpose of the Study

The purpose of this study is to explore, describe and conceptualize the provision of spiritual care to terminally ill patients and their families in hospice. The goals of the study are:

1. To describe the variations in religious, spiritual orientations among agency staff/volunteers, patients and their families;

2. To explore how staff, patients and their families define and experience "spirituality" and "spiritual care;"

3. To describe how staff assess the religious and spiritual needs and resources of patients and their families;

4. To describe and explore how staff and volunteers actually provide spiritual care:

5. To describe how patients and their families experience the provision of spiritual care;

6. To describe and explore an agency's provision of spiritual care based on the religious/spiritual backgrounds of its patients and families (e.g., Roman Catholic, Protestant, Jewish); and

7. To describe and explore how the agency facilitates or undermines the provision of spiritual care.

The overall intent is to ground the provision of spiritual care in human experience by identifying its meanings and practices.

Theoretical Framework for the Study

A linkage between religion/spirituality and health, particularly among the elderly and terminally ill, has been documented in studies. Hospice, which integrates spirituality within holistic health care, draws upon this linkage. "Whole person care" mandates more

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of health care professionals than simply treatment of the disease; it requires a broader orientation: the alleviation of suffering (Blount, 1993, p.28). Whole persons, not just bodies experience suffering; healing involves the whole person (Cassell, 1991). The National Hospice Organization (NHO) represents over 1800 programs in fifty states. The hospice principles of care follow:

1. Offer palliative (comfort-oriented), rather than curative treatment to afford patients an alert, pain-free life.

2. Treat the person, not the disease; the interdisciplinary team addresses the medical, psychological and spiritual needs of the patient and family.

3. Emphasize quality rather than length of life; affirms life and regards dying as a normal process, stressing human values that go beyond the patient's physical needs.

4. Consider the patient and the entire family as the unit of care (National Hospice Organization, 1992).

The current social work Code of Ethics (NASW, 1996) complements the hospice philosophy of care. Similar to hospice's focus on patients' rights, social work emphasizes respect for the individual and client self-determination. Finally, the study is guided by definitions of terms from the social work and hospice literature and from studies in the sociology and psychology of religion.

Importance of the Study

Knowledge about the integration of religion and spirituality within professional practice is clearly at an early stage of conceptual development. Attempts to address the religious, spiritual needs of clients have been hampered by deficits in meaningful terminology and

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practice approaches. Furthermore, no practice approach has been articulated which addresses social work's concern regarding the imposition on the client of the worker's personal belief system. This study addresses these deficits by describing in human terms the meanings and practices of spiritual care in hospice. In the process, it provides an example of professionals making affirmative use of their belief system with their clients. The resulting conceptualization of spiritual care makes a major contribution to the effort in social work to reintegrate religion and spirituality within the profession.

Scope of the Study

This study utilizes hospice as the context for defining terms and identifying practice approaches for the integration of religion and spirituality within social work practice. The selection of more than one hospice allows for diverse religious, spiritual orientations and conceptualizations of spiritual care. Participation by volunteers and varied professionals (nurses, social workers, physicians, aides) as well as clergy in each agency further broadens the perspectives of spiritual care obtained. The use of semi-structured interviews yields rich, detailed descriptions of spiritual care assumptions and activities. The interview questions ask the care providers to relate their work experiences to their own religious, spiritual belief system in order to obtain a holistic orientation to this type of care. Finally, interviews with agency administrators and review of agency documents identify organizational characteristics which affect the provision of spiritual care in each hospice.

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Definition of Terms

The following definitions of "religion" and "spirituality" are drawn from the literature and are employed as a point of departure.

> ***Religion*** refers to a system of beliefs and values expressed through meaningful rituals and use of symbols within a community or institution of people who share these beliefs and values.

> ***Spirituality*** refers to an internal, innate impulse to find meaning and loving, fulfilling reliationships in life. It may manifest itself through activity in a religious institution, and it may not.

The study explores the **religious, spiritual orientations** of hospice staff and volunteers, patients and their families. A person's religious, spiritual orientation is psychologically complex, involving beliefs, emotions, attitudes, values, behaviors and social environments, all combining to form a "sense of integrity" (Batson & Ventis, 1982, p.7).

Religious, spiritual concerns, according to Batson and Ventis (1982), differ from everyday concerns in terms of their comprehensive scope and their power to affect central perceptions of oneself. The author refers to this distinction when exploring the religious and spiritual needs and resources of hospice patients and families.

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Chapter 2: Literature Review

Introduction and Overview

Review of the social work, hospice and pastoral care literature as well as studies in religion and spirituality and terminal illness place this study in context. A chronological review of the social work literature documents efforts to identify acceptable terminology and reintegrate religion/spirituality within the profession's education, practice and research. Beginning with a few marginal voices, the issue enters the mainstream literature to become the focus of lively debates among scholars and practitioners. The hospice literature presents definitions of terms and documents efforts to develop instruments for the assessment of religious, spiritual needs; and frameworks for the practice of spiritual care. The pastoral care literature discusses dynamics related to spirituality and health and calls pastoral care counselors to increased involvement in hospice. Finally, studies on religion/spirituality and terminal illness discuss relationships between religion/ spirituality, meaning of life issues and the dying experience. These studies document the importance of religion/spirituality as a coping mechanism for the terminally ill.

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Social Work Literature

Introduction

"Secular social service is a recently arisen profession; until the late nineteenth century, most social welfare was connected with a religious impulse or auspice" (Marty, 1980, p.463). Puritan-Protestantism exercised a culture-shaping power up to the early twentieth century, pervading and molding the economic, political, social and psychological dimensions of American society. Humanitarian and social reform movements and the resulting social services were inseparable from the religious, moral missionary zeal of the church (Ahlstrom, 1972). The birth of the social work profession in post Civil War America coincided with the birth of "Social Christianity" and its multiple religious, humanitarian reform campaigns including the establishment of charity organizations in 1873 and settlement houses in 1886 (Hopkins, 1940; Lieby, 1987). Schools of social work were established in the early twentieth century during the "Age of Crusades" represented by the rise of child welfare, public health and mental health movements (Leiby, 1987).

Magnuson (1977) calls the years between 1865 and 1920 the critical period of conflict between science and religion which resulted in the dominance of secular social work. The earlier social impulse, motivated by religion, degenerated into conventional charity and remarkable complacency within mainline Protestantism (Niebuhr, 1932). Protestant

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theology bred individualism and denominationalism - justification by faith was more important than good works (Hugen, 1994).

> Protestantism, with its individualistic orientation, internal divisions and inability to organize the larger public...was not able to prevail against secular agencies better equipped to exploit a pluralistic environment" (p.95).

The rise of the modern city and religious and cultural pluralism rendered Protestantism less dominant. Finally, social work progressively adopted society's belief in modern scientific methodology to solve its social problems. The social work literature during this time reflects the conflicts between "godly" or "evangelistic" and "godless" or "secular" social work. Several writings describe the transmutation among a number of social work leaders of their religious missionary impulses into social science and humanism (Lovejoy, 1920; Duffus, 1938; Devine, 1939; Addams, 1964; Frederick, 1976). In its effort to become a profession with its own body of knowledge and expertise, social work progressively closed off elements of religious concern. When it appeared in the literature, religion was boxed in under entries like "Sectarian Agencies," and was addressed only when it referred to religious social service auspices.

Beginning in the 1950's, the literature reflects a renewed interest in religious and spiritual issues, an interest which has blossomed in the past fifteen years. This chronological review of the literature traces scholars' efforts to develop acceptable definitions of terms and conceptual frameworks for the reclamation and reintegration of religion/spirituality within the profession. The review reveals three significant trends. The first trend reflects the changes in definitions of terms. Initially using definitions which traditionally refer to

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Judeo-Christian beliefs and practices, the literature moves quickly to definitions which focus on the functions of religion, encompassing diverse religious, spiritual and philosophical perspectives (McGuire, 1981; Roberts, 1990). Scholars draw the distinction between religion and spirituality and the latter term acquires a progressively expansive quality, encompassing atheism and agnosticism as well as theism. Second, the literature begins with a rationale for the connection between social work and religion and moves toward developing theoretical frameworks for its application in education, practice and research. Third, the topic is taken seriously and moves from the margins to the mainstream of the profession. A few voices are joined by a growing number of perspectives, creating lively and at times vociferous debates.

The 1950's: Defining the Issue and Presenting Challenges

Definitions

Writers seeking to reclaim the connection between religion and social work at first reflect a Judeo-Christian religious orientation (Bisno, 1952; Biestek, 1956; Spencer, 1956). Spencer (1957, 1961) goes beyond Judeo-Christianity to make the important distinction between religion and spirituality. She offers definitions upon which other writers build. Religion "signifies a systematized body of beliefs and practices or an organized group of people who believe in certain doctrines about the nature of man and of man's relationship to the universe" (1961, p.162). Spirituality refers to those aspects of the individual concerned with "finding the purpose and meaning in life experiences; this search can occur without the person's being related to an organized church or making use of a

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systematized body of beliefs and practices" (p.162). Based on these definitions, she offers propositions which affirm universal spiritual needs, their importance in human functioning and the profession's need for knowledge and skill in this area of work.

Education and Practice

Spencer (1961) identifies educational and practice issues which scholars have studied for the past three decades. Questioning the profession's scientific humanistic philosophy, she asks if humanism is enough, or if social work education should also provide knowledge of the great systems of theology as a basis for persons' responsibility to others. Rather than focus only on religious beliefs and practices which are at times limiting, such education should emphasize the potential for religion and spirituality to enhance life. While advocating for this, she clearly articulates several challenges which remain today. Noting the plurality in spiritual and religious perspectives in American society and the diversity among social work students, faculty and educational institutions, she presents the challenge of selecting and adapting appropriate educational materials for various areas of the curriculum (Spencer, 1961). Exploring the social worker's responsibility to make use of religion in practice given the profession's diversity, she asks how the worker, regardless of the auspices under which she is employed, can help the client make affirmative use of her own religion (Spencer, 1957).

Keith-Lucas (1958, 1960) reflects Spencer's articulation of universal spirituality and develops in later works a framework for a "synthesis between social work and theology."

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defining the common theological and social work core as the divine and human helping process (1960, p.87).

The definition of religion during this decade moves beyond beliefs and practices of traditional Judeo-Christianity. Writers introduce the concept of spirituality, a universal human dimension, which can be present without an organized body or a systematized creed. A broad rationale for the incorporation of religion and spirituality within the profession is presented, including one person's initial effort to synthesize the two. Recognizing the complex implications for social work education and practice, the writers present challenges for future scholars and practitioners.

The 1960's and 1970's: Examining Parameters of the Issue

Practice

Existential philosophy provides the catalyst and underpinning for much of the literature in the 60's and 70's. Joining existentialism in reaction to the depersonalization of society, social work finds many areas of compatibility with this philosophy. Writers apply its concepts to practice, particularly casework and psychotherapy (Krill, 1966; McLeod & Meyer, 1967; Sinsheimer, 1969; Imre, 1971). The human relationship is central to existentialism and casework. The caseworker views the client as a fellow human being, and they are both moving towards higher levels of authenticity. Hence, the casework or

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therapeutic relationship is an active coming together or "communion, an experience in continuing, authentic self-disclosure and love" (Sinsheimer, p.72). This definition of the therapeutic relationship refuses the dehumanizing notion that to be a religious person is to enslave oneself to rigid laws of behavior demanded by an authoritarian, controlling God (Krill, 1966).

The literature reveals beginning efforts to understand the complex relationship between a worker's personal beliefs and her professional practice. Imre (1971) and Krill (1966) ask how a social worker's personal philosophy influences her practice. McLeod and Meyer's (1967) empirical study shows the strong effects, independent of professional training, of religious background on social work values. Several studies demonstrate the diversity within a given religion and the complex relationships between persons' beliefs and social change. The study by Allport and Ross (1967), using their Religious Orientation Scale (ROS) to measure religiosity, reflects the diverse orientations within a religion. Neal's (1964) study of the relationship between Roman Catholic priests' values and their attitudes toward social change shows the importance of personal frames of reference despite a common orientation to one religion. In a study based on survey data collected in 1964 and 1984, Reeser & Epstein (1990) discover varying relationships among social workers' levels of activism, professionalization and identification with religion or spirituality.

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Keith-Lucas (1962) further develops his conceptual framework, connecting the Judeo-Christian tradition to social work. The centerpiece of this framework is his analogy between the Christian trinity - Father, Son and Holy Spirit - and social work's provision of reality, empathy and comfort or support.

The North American Association of Christians in Social Work (NACSW) was incorporated in 1954 and first published its journal in 1974. Initially called The Paraclete, it was renamed Social Work and Christianity in 1979. Seeking to provide a forum for "Christians as they seek to integrate their faith with their practice" (Eckhardt, 1974, p.2), the early issues focus on defining a Christian theory or philosophy of social work practice (Kim, 1974; Eckhardt, 1977). Bower (1975) and Johnson (1977) present the Biblical basis for social concern and social action found in God's commandments and the life of Jesus Christ. Exploring the relationship between a "Christian world view" and social work practice, Hunter (1979) presents how six popular theologies explain the cause(s) of human suffering and prescribe the necessary interventions. Renetzky (1977) defines and discusses the spiritual dimension as inherent and innate regardless of one's theological or religious beliefs. According to his model, the spiritual dimension is the foundation for a person's biological, psychological and sociological dimensions, and a person's spiritual well-being greatly affects the other dimensions' ability to develop and to function. Consiglio (1979) discusses how the Christian perspective is compatible with and moves beyond the conceptual limits of social work practice by viewing a person as a:

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> ...meaning-giving, meaning-seeking being...with spiritual struggles for dignity, meaning and justice which lie behind all that happens in life which we call psychological and social problems (p.40).

Education

The first published attempts to integrate religion within social work education appear in Social Work and Christianity. The Spring, 1980 issue is devoted to "Christian Social Work Education." Keith-Lucas begins his definition of Christian Social Work by defining what it is not: does not impose a code of morals on clients; is not evangelistic; does not give higher priority than does the secular world to spiritual things; and is not opposed to science. The unique feature of Christian Social Work Education is: "the oneness of the Christian experience and that of serving others...the way in which they illumine each other" (p.6). In an article describing how to teach psychopathology, Johnson (1980) suggests that social work programs in private Christian colleges might provide leadership in ways to incorporate a client's religious faith into assessment and practice.

Research

Revealing the influence of existentialism, and joining in a growing debate within the profession, several writers assert that humanistic values should be afforded equal if not greater attention than scientific methods (Salomon, 1967; Watson, 1979). Describing qualities common to scientific empiricism and dogmatic religion, Watson (1979) emphasizes the danger of social workers becoming alienated from their subjective, human selves.

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Keith-Lucas (1978) states a Christian social worker's disagreement with scientism which "...denies any knowledge except that which is gathered through its methods" (p.4). Kim (1975) presents social work research from a theological perspective, arguing the scriptural basis for much scientific knowledge.

Elements of a theoretical framework for the application of religion/spirituality to social work practice, education and research are drawn from existentialism and Christianity. However, the literature also demonstrates the complexity of human nature. Studies of religiosity and personal belief systems show the diversity within a given religion and the multi-causal relationships among religious, spiritual beliefs, professionalization and social change.

The 1980's: Enlarging the Scope and Developing Models

Increasing interest in developing meaningful definitions of terms and in incorporating religion/spirituality within the profession is indicated by the fact that two thirds of published works on this subject appear after 1980. This interest was partially driven by concern over the privatization of religion, leading to a division between public and private ethics in a pluralist society. "The privatization of religion and the compartmentalization of social workers' professional and religious selves make it difficult for social work to even talk of the possibility of integration" (Judah, 1985, p.26). Refusing the distinction between "Godly" and "Godless" social work, Marty (1980) finds

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social work guilty of "boxing religion under sectarian agencies" (p.479). Siporin (1985) notes the profession's continuing neglect of the client's spiritual needs.

Practice

The continuing discussion of the relationship between personal beliefs and social work practice is enhanced by Reamer's (1983) discussion of the free will-determinism debate. Referring to Reamer, Faver (1986a) asks how underlying belief systems interact with situational variables to influence social workers' perceptions of the sources of clients' problems.

Writers in journals under Jewish and Christian auspices discuss the integration of one's personal beliefs within her professional practice. Two Jewish scholars present the issue as a conflict in values.

> A value is something assigned prime importance, an ideal cherished assiduously and tenaciously in the hope it will be actuated, brought to life and become identifiable in the behavior of people as individuals and as a collectivity (Bubus, 1980, p.232-233).

Bubis (1980) asks: "When social work values and Jewish values conflict, which values should a social worker and a Jewish agency choose?" His "Jewish answer" is, "It depends" (p.233). While asserting the need to combine professional and Jewish perspectives, he proclaims that social workers are "Klei Kodesh," holy tools and that social work is invested with a "transcendent purpose" (p.236). Danzig (1986) poses a similar question: "...whether and how personal and professional values...can be integrated

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on a level that goes beyond the oppositional phase wherein personal values stand versus professional values" (p.41). She presents strategies for the "religiously committed social worker" to integrate religious values within theory. Resolving this conflict is especially critical for a Jewish social worker because:

> Judaism recognizes no clear distinction between the realms of the religious and the nonreligious. Judaism explicitly brings the religious struggle into this world. The dedicated religious person need not and may not retreat into monasticism to live out his commitment. Rather, he tests out and lives it in his work, in his daily activities (p.48).

Sherwood (1981) makes a strong statement: "...all social workers, Christian and secular, bring faith-based values into their practice" (p.45). Articles in Social Work and Christianity evidence a greater specificity regarding means of incorporating faith into practice. While advocating the open expression of one's beliefs in appropriate situations, Sherwood (1989) and Horsburgh (1987) stress that "...there is no justification for the position of social worker as missionary" (Horsburgh, p.75). Bear (1980) introduces the NACSW "Code of Ethics" and asserts that it gives a primary place to the spiritual dimension in practice including appropriate use of prayer and scripture. Brown (1989) addresses the relationship between personal values and professional practice as dialectical for the first time in this journal rather than viewing it solely as the impact of values on practice. Two scholars respond to the profession's resistance to religion/spirituality. Ifill (1987) charges social work educators with indoctrination when they strongly discourage integrating faith into practice. Commenting on an agency's policy of refusing to allow the use of prayer with clients, Sherwood (1989) states:

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> ...to ignore the religious lives and values of clients is to be guilty of a highly reductionist and truncated view of what constitutes working with the 'whole' person-in-situation. Insensitivity, ignorance, devaluation or simply ignoring is just as professionally culpable in regard to religious issues as doing the same with minority, ethnic or cultural diversity issues (p.3).

Several scholars propose theoretical models for incorporating spirituality into practice. Faver's (1986a) framework explains how religious and nonreligious belief systems affect persons' attitudes toward social welfare. Rizzuto (1982) presents a notion of god as "the God representation." More than an abstract concept, this notion of god includes "internal weavings, unconscious feelings and ideas around internalized objects such as parents...It takes on all of the psychic potential of a living person" (p.15). Using this notion of god and Fowler's (1981) definition faith, Joseph (1987) presents a developmental model of the religious dimension through the life cycle. Each stage describes functional and dysfunctional aspects of religion and suggests phase-appropriate interventions. In her study, Joseph (1988) explores how social work practitioners deal with identified, salient religious issues emerging at various life stages.

In an effort to more effectively integrate social work theory and practice, Goldstein (1986) offers an approach which emphasizes an understanding of the client's life experiences. This "commitment to the client's subjective world also draws the worker into the ethical realm of the helping process, which is concerned with the deeply held normative and spiritual beliefs of both the client and the worker" (p.355).

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Education

Faver (1986b) offers criteria for content on religion/spirituality. The social work educator must help students to grapple with persons' basic assumptions about reality. This requires a personal, holistic and experiential education and a willingness to examine spiritual as well as cognitive ways of knowing. Advocating for the expansion of the "person-in-environment" paradigm to include relationships among the client, the social environment, the nonhuman world and ultimate reality, Canda (1989) presents an approach to social work education using a comparative analysis of religion and spirituality.

Research

Imre (1984), Judah (1985), Siporin (1985) and Faver (1986b) continue the debate over the deficits of scientific empiricism. The conflict between beliefs of science and religion leaves the professional with religious beliefs trying to hold two fundamentally incompatible understandings of reality (Judah, 1985). Faver (1986b) discusses how, if taken seriously, religion will profoundly influence social work research. Given the limitations on human ability to accurately apprehend ultimate truth, social workers should guard against arrogance that claims certainty and be open to multiple types and sources of knowledge without prejudging their validity.

Definitions

Borrowing from the sociology of religion, the social work literature reflects progressive use of functional definitions of terms (McGuire, 1981). Batson and Ventis (1982) present

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criteria for a functional definition of religion: uniqueness, complexity and diversity. Fowler (1981) refers to faith as a universal concern which predates being religious or irreligious and religion as one way of expressing one's faith. Several scholars adopt his description of the reciprocal relationship between religion and faith and his stages of faith development. Stating that spirituality cannot be subsumed under psychoanalytic or cognitive theories, Siporin (1985) defines spirituality as "that aspect of the person's psyche, conscious and unconscious that...strives for transcendent values, meaning, experience and development of knowledge of ultimate reality, belonging and relatedness with the moral universe and community..." (p.208).

Canda (1988a, 1988b) strives to develop a comprehensive, inclusive conceptualization of spirituality incorporating insights from diverse religious and philosophical perspectives.

> Spirituality refers to the total process of human life and development, encompassing biological, mental, spiritual and social aspects of the person. There is no dichotomy between the physical and the spiritual; it arises from an innate impulse to find fulfillment through establishment of a personal sense of meaning and loving relationship between individuals, society, the nonhuman world and the ground of existence - ultimate reality. Spirituality manifests in concrete ways for each person...it may manifest through affiliation with religious institutions, but it may not (p.35-36).

The literature demonstrates a growing sophistication during the 1980's. The complex relationship between personal belief and professional practice is addressed by several different perspectives. Functional definitions of terms account for the secularized, pluralist society and diverse spiritual perspectives. These terms are applied to proposed

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models for the inclusion of religious and spiritual content in social work education, practice and research.

The 1990's: Different Voices

Practice

The dialogue calling for the integration of religion and spirituality within the profession is joined by a growing number of "different voices" as this decade proceeds. Two writers present elements of the Jewish perspective. Levine (1990) labels artificial any separation between the study of religious teachings (Torah) and social action in the form of "chesed" (loving kindness) and "tzedakah" (philanthropy). Indeed, "...the purpose of study is to teach and motivate individuals to act...One implies and reinforces the other..." (p.44). Chizewer (1994) explores Martin Buber's concept of redemption as a means of repairing relationships between people, leading to a general repairing of the world. The social work profession and the Jewish concept of redemption are based on a belief in the human ability to change.

> Social work is my means of joining the process of repairing the world. As a participant in this healing process, my Jewish beliefs and my profession as a social worker join in harmony, because the profession of social work believes in a redemptive process similar to the one I find in Judaism (p.53).

Articles in Social Work and Christianity evidence a growing scope in terminology and specificity in methodology. Hammons (1991) uses Martin and Carlson's (1988) definition of faith:

> ...pertains to one's trust in the truth and value of his or her spiritual orientation in explaining and ordering the world, its events and inhabitants (p.60).

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She presents a framework for the integration of faith into social work assessment, intervention and evaluation and provides a continuum of strategies to resolve conflict in persons' world views. In his review of Loewenberg's book, Religion and Social Work Practice in Contemporary American Society (1990), Ressler (1991) criticizes the author for a narrow definition of religion, instead recommending the functional definition provided by sociology of religion. Since a person's faith orientation is developed in response to and in interaction with her physical and interpersonal environment, it is highly relevant to social work practice because it identifies what events mean to the client (Garland, 1991). She presents a model of appropriate Christian roles for the social worker based on the client's world view. Following an outline of three views of human nature and change, VanderWaal (1992) presents change as a developmental process in theological as well as psychological terms. Edwards (1996) presents guidelines for managing values conflict in practice. Wineberg (1996) reports results of one of the few studies on religion and social services at the macro practice level. His longitudinal (15 year) study of religious congregations in one community revealed an increasing responsibility for and participation in social services. He asserts the need for social work to become knowledgeable of religious communities and how to work with them.

> In effect, the religious community has become the broker of scarce charitable goods in an increasingly shrinking market of such resources (p.10).

Hugen (1994) informs his fellow Christian social workers that their biggest problem is a privatized faith which has narrowed the focus of integrating faith into practice solely to values issues. He calls for the broadening of this integration to the various practice

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methods (individual, family, group and community); and the development of theological understandings of the major social issues - poverty, social justice and human diversity.

Canda (1990) presents a holistic approach to the use of prayer in practice, emphasizing that this does not imply an exclusivist position that alienates or denigrates alternative forms of spirituality. He provides ethical guidelines for the use of this holistic, inclusive approach to prayer. Cornett (1992) calls for a "biopsychosociospiritual" model of human functioning.

Five studies examine religion/spirituality in practice. Sheridan et. al. (1992) report on practitioners' attitudes and behaviors toward religion and spirituality using Batson and Ventis' (1982) three dimensional model of ways of being religious. Although the respondents valued the religious or spiritual dimension in their own lives and respected the functions it serves for people, they expressed discomfort with its use in practice and 79% stated that religious or spiritual issues were rarely if ever addressed in their professional training. Rizer and McCulley (1996) found similar results with graduate social work students. Although 95% felt spirituality is important in their lives, 85% said it was absent from their education, and 64% did not integrate it into their practice. Derezotes and Evans (1995) examined the attitudes of 56 social workers in Utah towards spiritual and religious issues in practice. They found that: spirituality and religion are different but both should be considered with all clients; social workers must understand their own beliefs and biases and tend to their own spiritual growth; and social work

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education does not but should provide within the existing curriculum the knowledge and skills required for practice with these issues. DiBlasio (1993) tested the differences between a group of strongly religious social workers and those with less religious conviction on attitudes toward and use of forgiveness and religious openness. Results revealed no significant differences between the groups except the strongly religious group were more receptive to the idea of forgiveness. The majority of all the workers believed that religious ideologies should be completely separate from their practice. Millison (1994) reports the effects of religiosity upon the practice interventions of religious and nonreligious Jewish social workers. A worker's religiosity was determined by self-declaration and by religious observance (i.e., attendance at religious services, observance of religious rituals). Millison found that religious social workers employed more treatment approaches defined as spiritual than nonreligious social workers. However, the auspices of the worker's agency and the type of clients served also influenced the worker's practice.

Several models incorporating "the spirit" into practice are offered. Nakhaima and Dicks (1995) utilize a religious consultant in the process of counseling with rural religious families. Brown and Romanchuk (1994) use logotherapy, an existential psychotherapeutic approach, with the aged. Smith (1995) applies the Transpersonal perspective to practice.

> The Transpersonalist perspective posits that the psychosocial problems in our society are associated with spiritual factors and this requires a paradigm shift in social work practice that incorporates spiritual content (Derezotes & Evans, 1995, p.42).

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She presents the "transegoic" model of transpersonal intervention for use with people confronting their own mortality. Morrell (1996) promotes a "sociospiritual approach" to substance addiction. She scolds radical or progressive social workers for neglecting the spiritual dimension, reminding them that: "Spirituality can inspire and sustain people to move beyond external and internalized oppression" (p.309). She calls for overcoming the false separation between politics and spirituality by focusing on interconnectedness. While identifying different ways of listening to religious content in therapy, Goldberg (1996) emphasizes the clinician's dilemma regarding the proper stance to take toward religious data. "...the reality of the transcendent lies outside our area of expertise." Hence, religion at times occupies a "privileged position,...immune from psychological interpretation" (p.135).

The establishment in 1990 of the Society for Spirituality and Social Work and its journal, Spirituality and Social Work is further indication of the growing professionalization of this topic in social work. The Society is "...dedicated to promoting dialogue and mutual understanding among social work scholars, students and practitioners who strive to provide spiritually-sensitive services" (Canda, 1990a, p.1). Writers reflect on previously stated definitions of spirituality, a universal human experience, which has a functional, non-dualistic, inclusive base (Canda, 1990; Siporin, 1990; Logan, 1990; Constable, 1990). Two issues deal with the contemporary struggle to include Christian perspectives specifically and spiritual issues in general within social work education (Judah, 1992; Ortiz, 1991; Ressler, 1992). Two articles, one by a service consumer and one by a

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professional, present the power of religion and spirituality with persons suffering from mental illness and substance addiction (Simons, 1992; Sullivan, 1992). Other articles present Native American (Chenault, 1990), Gandhian (Capossi, 1992), Eastern Psychology (Singh, 1992) and Karma Therapy (Seplowin, 1992) approaches to social work practice and education. Canda (1992a) provides an updated bibliography of diverse religious, spiritual perspectives. The Spirituality and Social Work Journal merged in 1994 with the journal Social Thought: The Journal of Religion in the Social Sciences. The Society still publishes a newsletter twice a year for its members.

Education

Kilpatrick and Holland (1990) provide some practical ways for students and practitioners to think about the spiritual dimension and to provide appropriate interventions. Based on information gathered from social work educators regarding the place of spirituality in the curriculum, Dudley and Helfgott (1990) make specific recommendations. Netting et. al. (1990) present a rationale and methodology for the incorporation of content on religious institutions into existing courses in policy, administration and community practice. Denton (1990) recommends educational content to prepare students for work with religiously fundamental families.

Two articles in Social Work Christianity address education. Blake's (1994) content analysis of 59 college catalogs shows no educational content on world view (religion, spirituality, faith) in any of the government sponsored undergraduate and graduate

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schools and in 79% of the religious-sponsored graduate programs. Furman (1994) discusses a course she has taught, "Spiritual and Religious Dimensions of Social Work Practice," as relevant content in preparing "culturally-sensitive practitioners" (p.103).

The increasingly acrimonious debates surrounding religion and social work education entered the mainstream in this decade. The question: "Should social work education address religious issues?" is debated in "Point/Counterpoint" of the Winter, 1994 edition of the Journal of Social Work Education (Amato-von Hemert & Clark). Amato-von Hemert argues that social work is mandated by its code of ethics to address religion in practice in order to foster client self-esteem, avoid discriminatory practice and strengthen cultural diversity. Clark points to problems in assessment due to lack of meaningful terminology; and argues against social workers' being trained to be "pastoral professionals." The larger issue, he believes, is to prevent a group within the profession from placing religion in "an ascendant position in social work education, practice and research," thereby risking the loss of professional stature (p.14-15). In the same issue, Cowley and Derezotes present a rationale for incorporating Transpersonal Psychology within social work education. The fourth of the four Western psychological theories, Transpersonal theory is the only one which focuses on the spiritual dimension. The authors argue that this may be the only paradigm sufficient to deal with the complex social, cultural and global issues of the "post modern world" (p.37). The issue has also appeared at the governance level within the profession. After two decades of silence on the issue, the Curriculum Policy Statement and accreditation curriculum standards

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implemented in 1995 by the Council on Social Work Education (CSWE) contain references to religion and spirituality. Finally, in a revision of nondiscrimination standards for candidate programs, the Council has proposed an exemption for religious institutions from the clause regarding political and sexual orientation (1996).

Research

During the latter 1980's and into the current decade, scholars who are engaged in the effort to integrate religion/spirituality within the profession participate in debates around the preferred methods of knowledge building. Witkin (1991) presents the debate, indicating two major, concurrent developments in social work during the previous 15 years: the empirical clinical practice (ECP) model which is based on scientific empiricism; and the emergence of a literature critical of this orientation toward research and practice. The debate becomes vociferous and stinging at times, and proponents of both perspectives appear to present their case as the minority voice. Hartman (1992) talks about knowledge as power and describes how the privileged scientific methods have subjugated "local, popular, indigenous knowledge located at the margins of society" (p.483). She calls for social work to participate with clients in the "insurrection of subjugated knowlege" in research and practice (p.484). Imre (1994) discusses the term "knowledges" as opposed to one body of knowldge that everyone accepts which implies some kind of scientific base as fact. She welcomes "knowledges that widen our horizons, not limiting them to what we can see now" (p.7).

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Barber (1996) also sounds like a minority voice when he presents the debate as the profession's historical resistance to the scientific method. In his analysis of the political, philosophical and "quasi-religious" sources of this resistance, he draws the distinction between "religious authority for acquiring knowledge" and scientific knowlege building which is capable of "falsificationism" (p.380). Suggesting that many social workers consider their job more as a religion than an occupation, he indicates the danger of raising practice methods to the level of unquestioned religious beliefs, resisting empirical investigation and risking harm to clients as a result.

Conclusions

Social work literature devoted to the interface between religion and social work reflects significant progress in the effort to reintegrate the two. Scholars have dealt with the longstanding suspicion that religion is fundamentally incompatible with social work practice principles. A conceptual framework for the integration of religion/spirituality within social work practice which includes proposed models and specific approaches has been developed. However, a conceptual scheme to assess religious, spiritual issues needs to be developed and further research should be conducted to clarify the complex relationships between the social worker's personal belief system and her practice. Specific approaches and courses have been offered, but a systematized body of knowledge and skills must be compiled in order to appropriately incorporate the content into education. Terminology that accounts for the plurality in society and within the profession has been offered but is not universally accepted by social workers. Finally, the reintegration of

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religion/spirituality within social work has assumed a place in the mainstream literature and governance of the profession. The few marginal voices in the 50's, 60's and 70's have been joined by progressively diverse perspectives in the past 15 years. What was once a polite exchange of ideas has developed into vitriolic and bitter debates at times, an indication of the growing political and ideological power of the issue.

Hospice Literature

Introduction

A careful reading of the hospice literature reveals a developing consensus around definitions of and distinctions between "religion" and "spirituality," but no agreement regarding the meaning of "spiritual care." In Millison's review of the literature on spiritual care in hospice (1995), this social work scholar notes that the topic has received increasing attention, particularly in the past five years. His research recommendations provide an indication of the current state of knowledge in the field. They are: to develop a standard spiritual assessment instrument; to identify what spiritual care techniques work best with what type of patients; to determine who should provide spiritual care and the appropriate training required; and to conduct more research on the spiritual needs of special patient populations (i.e., AIDS patients, children, persons of color).

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This review is organized into four topic areas which facilitate an understanding of the issues involved in this descriptive, conceptual study. The first two deal with the actual definition of concepts. The last two apply concepts to practice.

Definition of Concepts

The literature has developed to the point that the most current articles refer to others' definitions or present reviews of the literature (Berggren-Thomas & Griggs, 1995; Dudley et. al., 1995). Emblen (1992) reviewed the nursing literature between 1960 and 1990 for definitions distinguishing spirituality from religion. The following definitions emerged from a concept analysis of the literature:

Religion: System of organized beliefs and worship which the person practices.

Spirituality: Personal life principle which animates transcendent quality of relationship with God or god being (p.45).

The two terms share only eight out of 116 key words in common, suggesting major differences in the concepts which, if used interchangeably, would result in inaccurate interpretations of meanings. The review reveals a trend in the literature from no distinction between the concepts to a definite distinction with a change in emphasis from religious to spiritual care. To explain this change, Emblen reminds the reader of the historical relationship between nursing and religion. Nursing care grew out of religious teachings that emphasized care for the sick. In the Western world, the hospital is the product of centuries of Christian beliefs and practices.

> The primitive hospital movement is everywhere found to have been closely allied to religion, and frequently the hospital was the temple, and the 'doctors'

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> and 'nurses' the ministers, both men and women, who served the temple (Cox, 1955, p. ix).

According to Emblen, the secularization of America in the 1960's and 1970's and the introduction of holistic and humanistic values into nursing expanded the religious to a spiritual emphasis.

Scholars and practitioners have drawn distinctions between "religion" and "spirituality" in several ways. One way presents spirituality as the larger concept. The spiritual dimension includes the religious, but is not confined to that dimension (Millison, 1988; Amenta, 1988; Irion, 1988; Munley, 1983). A second distinction refers to the source of the two concepts. According to Blount (1993), the spirit is the innate essence of what it is to be human; the dimension of personhood pertaining to values and meaning. Religion is a belief system that enables conceptualization and expression of spirit. It is a construct of human making. A third way scholars differentiate the concepts is through their expression. Religion refers to the external expression, through practices, rituals and membership in a community, of a person's beliefs and values regarding human existence (O'Connor, 1988; Amenta, 1988). Spirituality may or may not be expressed externally but refers primarily to internal processes (O'Connor, 1982). Blount (1993) defines qualities of the spirit. Spirit is experienced, not proved; it is indirectly observed through the body and mind. Spirit is also relational in its expression; that is, it is expressed in relationship, in dialogue, in communion with others.

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Burkhardt's (1989) review of the literature on "spirit" reveals usage of the concept in four categories: spirit/spiritual, spiritual dimension, spiritual well-being and spiritual needs. Spirit/spiritual refers to the essence of a person; a belief or personal quest that gives meaning to existence; a relationship with a Higher Being; and personal transcendence beyond the present context of reality (Hirano, 1978; Colliton, 1981; Conrad, 1985; Burkhardt & Nagai-Jacobson, 1985; Granstrom, 1985; Soeken & Carson, 1987). Spiritual dimension has been described as a unifying and integrating force within individuals; and a common bond between persons (Colliton, 1981; Highfield, & Cason, 1983; Granstrom, 1985; Sodestrom & Martinson, 1987). Spiritual well-being has been defined as harmonious interconnectedness with self, diety, community and environment; and the health of the totality of the inner resources of a person (Munley, 1983; Hungelmann et. al., 1985; Miller, 1985; Soeken & Carson, 1987). Spiritual needs refer to the deepest requirement of the self; and a lack of any factor necessary to be in a dynamic relationsship with a Higher Being (Fish & Shelly, 1978; Stoll, 1979; Colliton, 1981; Ellenhorst-Ryan, 1985). All of these definitions derive from the contrast between the immaterial, incorporeal and the physical dimensions of reality.

Definition of the Conceptual Problem

The distinction between "religion" and "spirituality" appears to be understood intellectually, but confusion emerges when meanings are put into practice in the actual provision of "spiritual care." While palliative care of the body and mind is guided by science in most persons' minds. "When the topic of spirit is raised, we stumble on the

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barriers and semantics erected by religious thought, and our personal positions as Christian, Jew, humanist or agnostic can easily interfere" (Mount, 1993, p.34). The challenge is doubled since hospice patients and their families present the same spectrum of beliefs and values. Without an agreed upon frame of reference, practitioners bring their personal frames of reference to practice or prefer to avoid the matter and refer "religious issues" to the clergy. Studies have demonstrated care providers' narrow definitions of "spiritual concerns" and the consequent underreporting of patients' spiritual needs (Highfield, 1992; Highfield & Cason, 1983). Even when they acknowledge the important role that spirituality plays in the life of the terminally ill person, the practitioner is confronted with the problem of how to utilize that knowledge on behalf of the patient. Questions of the spiritual care provider's role and approprate behavior reflect concern over the imposition of religious or spiritual beliefs on dying people, a concern which haunts those who wish to support this aspect of care. A few writers have struggled with this issue from within their humanist (Foster, 1986), Jewish (Feifel, 1977; Klagsbrun, 1982 & 1986; Lamm, 1988; Kensky, 1992), Buddhist (Lief, 1986) and Christian (Beisheim, 1988; Demske, 1988; Head, 1993) orientations. However, no unifying, integrating orientation to the practice of "spiritual care" has been developed which is acceptable to hospice care providers who represent a wide spectrum of beliefs.

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Assessment of Spiritual Needs

The Joint Commission on Accreditation of Hospitals (JCAH), Medicare and the National Hospice Organization are the regulatory and governing organizations for hospice. They have developed guidelines, such as appropriate staff (i.e., pastoral counselor), for meeting persons' spiritual needs, but there are no definitions of "spiritual needs" or standards for spiritual assessment. Several authors have attempted to address these omissions by naming categories of spiritual needs and by developing assessment instruments. Most instruments contain some variation of the categories "spiritual concerns," "spiritual distress," "spiritual pain" and/or "spiritual despair." The Third National Conference on Classification of Nursing Diagnoses (1978) recognized the importance of spirituality by including these terms in the list of approved nursing diagnoses. In 1980, the Fourth National Conference combined these four into one category, "spiritual distress," defined as "a disruption in the life principle which pervades a person's entire being and which integrates and transcends one's biological and psychosocial nature." In an effort to operationalize this definition, Hay (1989) breaks "spiritual distress" into two categories: "spiritual suffering" which is interpersonal and/or intrapsychic anguish; and "inner resource deficiency," or diminished spiritual capacity. Noting the fact that his instrument is designed for use by various professional disciplines, he includes psychosocial characteristics in his four categories. O'Connor (1993) distinguishes between "spiritual issues," "spiritual needs" and "spiritual pain," emphasizing the need to assess each one carefully. "Spiritual issues" reflect a person's spiritual orientation and may include nurturing the soul, the solace of religious traditions and a connection to humanity.

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"Spiritual needs" may range from specific religious rituals to secular observances (music, poetry, nature). O'Connor does not define "spiritual pain" beyond referring to some patients' belief that they are being punished by God. Rather, she focuses on the spiritual care providers' drawing upon the person's religious, spiritual resources to address her pain. Kemp (1994) identifies basic spiritual needs – meaning, hope, relatedness and forgiveness – and parameters for their assessment.

Several assessments of spiritual needs distinguish between religious and spiritual needs. Stoll (1979) divides spiritual needs into four categories. Two are religious: a person's concept of God or deity, and the significance of religious rituals and practices to the person; and two are spiritual: the person's source of strength or hope, and the person's perceived relationship between her spiritual beliefs and her state of health. Similarly, two of Hay's (1989) four categories refer to religious needs: belief system problem, and religious request. Amenta (1986) recommends having two sets of questions: one for patients affiliated with a congregation and one for the non-affiliated. Fitchett's "7 X 7 Model" (1995) has two subdivisions - holistic and spiritual - with seven dimensions in each.

An alternative approach to assessing spiritual needs is the evaluation of "spiritual well-being" (SWB) which has been defined by the National Interfaith Coalition on Aging as "the affirming of life in a relationship with God, self, community and environment that nurtures and celebrates wholeness" (Ellenhorst-Ryan, 1985, p.94). Several writers have

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identified similar indices of spiritual well-being. Epperley (1983) identifies the need for meaning, relatedness, hope and love; Highfield & Cason (1983) the need for meaning and purpose, to give and receive love and for hope and creativity; and Ellenhorst-Ryan (1985) for forgiveness, hope, love, trust and purpose of life. Two measurement tools, the SWB Scale and the Religious Well-Being (RWB) Scale (Paloutzian & Ellison, 1982) have been used in studies and their limitations have been recognized. Kirschling and Pittman (1989) found the scales have high internal reliablility but low construct validity. Moberg's (1982) Indices of SWB represents a major attempt to demonstrate the multifaceted nature of SWB. However, the instrument is somewhat lengthy and, like the aforementioned scales, reflects a Judeo-Christian perception of religious well-being.

Dudley et. al. (1995) conducted a content analysis of spiritual assessment forms used by agencies. Their findings are further indication of the lack of: definitional standards of assessment; concensus around meanings of "religion" and "spirituality"; and integration of spiritual with other interdisciplinary assessments. An article in The Hospice Magazine (1996) reflects the growing influence of managed health care and the emerging science of outcomes measurement.

> Enhancing the quality of life of patients is the very raison d'etre of every intervention in palliative care. Therefore, it is essential that there be a valid and reliable means of measuring quality of life in the terminally ill (Cohen & Mount, 1994).

The article briefly describes two quality of life assessment tools, both of which include assessment of the "existential," "transcendent" or "transpersonal" domains.

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Approaches to Spiritual Care

The primary task of the hospice spiritual care provider is to create an environment in which the person's religious, spiritual needs and resources are recognized and the person's spirituality is allowed to fluorish (Foster, 1986; Wald, 1989). According to Doka (1983), the caregiver should provide the terminally ill patient time for personal reflection, help her find meaning in her past and current experiences and allow enough space for the patient to interpret death. Nagai-Jacobson & Burkhardt (1985) assert the importance of the nurse's understanding of herself as a spiritual being to facilitate the experience of spirituality with others. Munley (1983) describes three goals of spiritual caregiving: fostering integrity with persons, promoting interpersonal bonding, and respecting and enhancing personal quests for meaning. Burkhardt (1989) proposes the concept of "spiriting" to further describe the process involved in this interconnectedness. The caregiver seeks to facilitate the harmonious interconnectedness within and between persons as well as with the physical environment and with the Ultimate Other. Fostering a sense of connection with that which is held sacred by the patient is part of the spiritual caregiver's role.

Several approaches have been presented from within specific religious, spiritual orientations. Rosen (1988) points to the well documented connection between religion/ethnicity and attitudes toward pain, suffering, illness and death. A Jew who values her present life over any death, a Christian who believes in an afterlife, and a Buddhist who believes in reincarnation will express profoundly different attitudes toward

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impending death. The spiritual caregiver must listen for and recognize these varying orientations. Foster (1986), a social worker and one of the founders of the American hospice, searches for a framework for her spirituality as a humanist. She poses the question: how do the professional's values and belief orientations impact on the nature and quality of hospice work? She proposes three options for the professional: to immerse herself in the patient's belief system; to explore beyond the patient's belief system, interpreting and using her own orientation; or to focus on other aspects of the person and collaborate with other staff (clergy) for spiritual care. In the end, she states that it is sufficient for the humanist to create an environment where the patient's, family's and staff person's voices are heard, human connections are made and no feelings, no matter how irreverent, are shut out. Feifel (1977), Klagsbrun (1982 & 1986), Lamm, (1988) and Kensky (1992) provide Jewish perspectives on the ethics and dynamics of spiritual care. Lief (1986) presents the concept of compassion as the orienting premise for spiritual healing in the Buddhist tradition.

Since 1990, several writers have identified components of spiritual care or specific intervention methods and one author places these practices within a spiritual care process. O'Connor (1993) discusses four elements of spiritual care: presence, compassion, hopefulness and the recognition that, although life may no longer be productive, it remains nonetheless fruitful. Kemp (1994) echos O'Connor in his discussion of spiritual care interventions and focus on the spiritual care relationship. Jones and Churchill (1994) present "archetypal healing methods" which include: life review therapy; presence:

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clinical hypnosis; myths, symbols, rituals and community; and "creative therapies" such as art and music. Derrickson (1996) presents an approach to understanding and encouraging the "spiritual work" of the dying. Spiritual care, according to Derrickson, may be in the form of "spiritual support" or "spiritual intervention" or both. Every member of the interdisciplinary team is capable of "spiritual support" which recognizes the person's spiritual work, listens and encourages it. Spiritual counselors or chaplains provide "spiritual interventions" or attempts to help people deal with a spiritual question, spiritual distress or a spiritual crisis. Derrickson offers a framework for the spiritual work of the dying which includes recurrent themes of: remembering, reassessing, reconciliation and reunion. Zerwekh (1993) presents ten competencies of hospice nurses in the context of a spiritual care process which moves from "caring spiritually" to "guiding letting go."

Scholars have endeavored to identify the distinctive issues involved in providing spiritual care. Steeves and Kahn (1987) explore the phenomenon of "experiences of meaning" among hospice patients and families and discuss how one may "create an atmosphere calm enough in the midst of suffering to allow the phenomenon to occur" (116). Burnard (1987) asserts that basic counseling skills are not sufficient since the caregiver is dealing with matters which affect the person's whole sense of meaning. Counseling in the spiritual realm can also tax the caregiver's own value and belief system and challenges the counselor to work with a situation where there are no answers. While not imposing her own belief system on the patient or otherwise getting in the way of a person's spiritual journey, the caregiver must get involved with the dispirited person, a difficult yet very

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important balance to achieve. In her study of the nurse-family spiritual relationship, Stiles (1990) finds that the spiritual dimension of nursing is "being with" rather than "doing to" patients and families. The spiritual relationship means being fully present as well as providing knowledgeable and skilled nursing care. Finally, practitioners have expressed the fact that providing spiritual care can be the loneliest part of hospice work. Reflecting the anxiety felt by professionals seeking to understand their own spirituality and how to approach this aspect of care in a pluralistic society, Foster (1986) says, "I find myself still alone, seeking a framework but unable to find the words" (p.101). At the same time, spiritual care can represent the most personally enriching aspect of caregiving. In his examination of the role that spirituality plays for caregivers, Millison (1988) finds a common thread running through their experiences: a heightened spiritual experience within themselves and with their patients and families which encompasses and transcends all other aspects of their work.

Particular issues are encountered when approaching the care of persons with AIDS (PWA's) in a hospice setting. Sister Patrice Murphy (1986) encourages the pastoral caregiver to look after her own wounds while endeavoring to heal the wounds of PWA's and their families. Schofferman (1987) and Baker and Seager (1987) describe psychosocial issues unique to PWA's, including prejudices such as homophobia and fear of contagion. The types of and approach to care will also be affected by early onset of dementia, poor baseline health and substance abuse among some patients. Finally, bereavement can be complicated by alienation from the family of origin, and by young

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surviving lovers, inexperienced at loss, and yet also at risk for the disease. Wendler (1987) offers guidelines for hospice in dealing with the psychosocial difficulties experienced by PWA's. Wallace (1990) discusses the feelings of fear and mistrust experienced by some PWA's at the thought of referral to hospice. Martin (1991) goes a step further and raises questions about the appropriateness of the hospice model for PWA's and what alternatives exist for those with no primary caregiver or no home. A few studies have identified spiritual care approaches helpful with this population. Anderson et. al. (1993) find "religious healing," through visualization and guided imagery, and meditation to be highly rated alternative therapies by PWA's. Gay men with HIV infection in Kendall's study (1994) identify issues of wellness as primarily a spiritual process emanating from "the soul." The empirical study by Somlai et. al. (1996) reveals a strong relationship between spirituality and psychological adjustment and coping. The authors conclude that a combination of spiritual traditions and mental health approaches are needed to facilitate the coping of persons living with HIV and AIDS.

Pastoral Care Literature

A review of the pastoral care literature reveals a few articles relating directly to hospice. The Spring/Summer 1980 issue of the Journal of Pastoral Counseling is devoted to the hospice movement and contains articles introducing its history and philosophy of care. The other major source of pastoral care literature is The Journal of Pastoral Care. Noting the inclusion of the "pastoral counselor" in hospice regulations for services, Gates (1987) calls on hospice clergy to expand their role and to demonstrate their competencies by

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teaching other professionals the techniques of pastoral counseling. Thomson (1994) invites pastoral counselors to join the hospice movement, noting that most counseling is being provided currently by social workers. Rutland-Wallis (1996) presents hospice as a unique setting for clinical pastoral education and care. In hospice, she says, "Pastoral care enters into personal meaning-making" (p.48).

Other articles relate to issues of spirituality and health. Opendaker (1975) discusses the dynamics of dealing with pain "in a faith context," based upon Biblical principles for understanding human suffering. Carfagna (1990) encourages professional caregivers to focus on spiritual factors as a powerful means of sustaining helping relationships. Van deCreek and Smith (1992) measure the spiritual needs of hospital patients and their families using existing assessment instruments. In a later article, Van de Creek et. al. (1995) introduce INSPIRIT, or the "Index of Core Spiritual Experiences" which, they find, measures a person's "intrinsic religiosity." Two articles noted elsewhere in this review address pastoral care for PWA's (Wendler, 1987; Somlai et. al., 1996).

Studies on Religion/Spirituality and Terminal Illness

Introduction

Studies conducted in the fields of sociology and psychology of religion and oncology nursing have demonstrated relationships between religion, spirituality and meaning of life issues on the one hand; and suffering, illness and the dying experience on the other. They

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also clearly document the importance of religion/spirituality as a coping mechanism for the terminally ill person during her final stage of life.

Religious, Spiritual Issues and Terminal Illness

In his classic, The Denial of Death, Becker (1973) describes the paradoxical nature of being human - the synthesis of "the soulish and the body" (p.69). The individual is:

> ...split in two: he has awareness of his own splendid uniqueness (soul) and yet goes back into the ground...to rot and disappear forever (p.26).

Hence, fear of death is universal and the individual tries to deny or overcome this "grotesque fate" (p.27). The only way, according to Becker, for the person to get beyond the natural contradiction of his existence is:

> ...the time-worn religious way: to project one's problems on to a God-figure, to be healed by an all-embracing and all-justifying beyond (p.285).

A number of studies have explored the relationship between terminal illness and religion/spirituality. Weisman and Worden (1967-77) use the term "existential plight" to describe the experience of people during the first 100 days following a cancer diagnosis when concerns about the meaning of life, illness and death predominate. Taylor (1993) finds that a terminally ill person's sense of meaning is integrally associated with the physical and psychosocial effects of her illness. Frankel (1959) defines "will to meaning" as the desire to give life meaning or purpose, to actualize values; a primary motivational force of people. Using Frankel's definition, O'Connor et. al. (1990) discuss how terminally ill people question the personal significance of their circumstances in order to give the experience a purpose and place it in a context of their total life. Moberg (1982),

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Hine (1982) and Mudd (1981) find spirituality is integral to the dying person's achievement of the developmental task of transcendence. Several studies show how spiritual manifestations of transcendence are significant in the person's final hours and days of life (Augustine, 1975; Kopes, 1981; Hood, 1983; Bacon, 1984).

Several studies have been conducted with hospice patients. Lewis et. al. (1986) find that these patients impart meaning or purpose to their situations, creating a world in which they have some control. Patients and their families interviewed by Steeves and Kahn (1987) describe "...experiences of the whole person that brought them in touch with something that they considered to be greater than or outside of themselves" (p.115). Patients who attribute some meaning to their experiences with cancer can be lead to a creative self-actualizing experience (Granstrom, 1985).

Spirituality and Coping with Terminal Illness

Weisman (1972) points to the increasing scientific interest in the psychology and sociology of death as evidence of humanity's ongoing fear of death. In his classic study, On Dying and Denying, he explores how terminally ill people adapt to the personal reality of their own death and identifies for the first time factors which can facilitate an "acceptable death" (p.150). Later studies document the importance of religion/spirituality as a mechanism to cope with the fear of death.

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Koenig (1988) establishes a relationship between persons' use of intrapsychic religious behaviors and feelings and reduced fear of death. Cancer patients with strong spiritual values show less fear of death and positive death perspectives (Gibbs and Achteberg-Lawlis, 1978). Similarly, Meyer & Altmaier (1992) find that a pro-religious orientation positively influences the coping process of persons diagnosed with cancer. O'Connor et. al. (1990) and Baldree et. al. (1982) identify faith and spiritual behaviors among the factors most commonly used by people faced with cancer and other life-threatening illnesses. In Miller's study (1985), chronically ill adults demonstrate a higher level of spiritual well-being (SWB) than healthy adults, leading her to conclude that chronic illness is a factor stimulating a person's valuing religious faith in God and a relationship with God. Kaczorowski (1989) finds an inverse relationship between SWB and state-trait anxiety, supporting her hypothesis that anxiety is lower in highly spiritual people confronting life-threatening illness. Reed (1986) discovers support for two hypotheses: first, terminally ill hospitalized adults indicate greater spiritual perspective than non-terminally ill hospitalized patients and healthy non-hospitalized adults; second, spiritual perspective is positively related to well-being among terminally ill hospitalized adults. Smith et. al. (1993) find a significant negative correlation between a person's level of transpersonal development (the relationship between one's personal perspective on death and one's level of spiritual awareness) and her level of psychosocial distress. Ita (1995) finds spirituality negatively related to death anxiety among hospice patients.

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This section of literature review began in the early 1970's with Becker's initial articulation of the concept of death anxiety. Since then, studies have revealed the complexity of this concept and its multiple possible determinants. Tomer and Eliason (1996) present an "integrative, comprehensive model of death anxiety" and postulate three immediate antecedents including the "meaningfulness of death" defined as a multidimensional construct related in complex ways to a person's philosophy, religion and life circumstances. "Meaningfulnnes of death" is determined by one's beliefs about the world and about self. The religious belief in an afterlife is only one way to make death meaningful. A strong belief in a just world, or death as reabsorption into a universal consciousness or cosmic unity also make death meaningful.

Conclusions

The social work and hospice literature reveal a growing concensus regarding the meanings of "religion" and "spirituality" and differences between the two concepts. However, no agreed upon conceptual framework exists for the actual rendering of spiritual or pastoral care in a multicultural society. The linkage between religion/ spirituality and health has beeen documented. Hospice, which provides spiritual care, draws upon this linkage and presents a favorable context for a study of the integration of religion/spirituality within practice.

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Chapter 3: Methodology

Introduction and Overview

The foregoing literature review demonstrates the need for a descriptive study that leads to a conceptualization of "spiritual care." The literature also identifies qualities of the subject which point to a qualitative inquiry as the preferred approach. The terms "religion" and "spirituality" are abstract concepts "thought of apart from any particular instances or material objects; not easy to understand; abstruse" (Webster's, 1988, p.5). When the focus of a project is the definition of an abstract concept, it is important that the study's parameters not be prematurely limited and that the methodology elicit a maximum amount of descriptive and detailed information.

Qualitative inquiry is naturalistic, not controlled, and takes a holistic approach to the study of a subject which is sensitive to context. This approach also facilitates adaptability of the study design as understanding deepens. Finally, inductive analysis of or immersion in the details of the subject produces categories or dimensions which are the desired product of the project (Patton, 1990). It is clear that a qualitative approach would best accomplish the goal of this study: to describe and conceptualize spiritual care in hospice.

A presentation follows of this project's research design which includes: a rationale for selection of the phenomenological method; a description of the data collection

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techniques; and an explanation of the procedures used in the analysis of the data and organization of the findings.

Phenomenological Method

A qualitative research design gathering descriptive information was utilized to explore the provision of spiritual care. One can extrapolate from the literature on religion/ spirituality and death and dying several dimensions of spiritual care. Contextual dimensions include the essence and functions of the terms "religion" and "spirituality" and persons' religious/spiritual issues associated with the experiences of dying and death. The primary dimension and focus of this study is the spiritual care process - the essence and structure of providing and receiving spiritual care. The phenomenological method was employed to explore this process, identifying the core meanings of the spiritual care experience.

Douglas and Moustakas (1985) present differences between phenomenological and heuristic research methods. Phenomenology encourages a detachment from the phenomenon through the researcher's suspension of her own beliefs and biases, while heuristics emphasizes relationship and presence of the researcher in gathering and analyzing data. Phenomenology results in definitive descriptions of the structures of experience, while heuristics leads to portrayal of the personal significance of the experience. The phenomenological approach is most appropriate for this study, given its end goal of a definitive description of the spiritual care process. This approach requires

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immersion in the world of hospice spiritual care while, at the same time, maintaining an analytical orientation. Although it presents a challenge, the writer found this detachment from the phenomenon desireable, since the desired product was a description of spiritual care as practiced and experienced by its providers, not the author.

The above methodology was employed in a manner which sought different conceptualizations of spiritual care rather than a single conceptualization. The hospice literature provides some categories concerning spirituality, spiritual needs and spiritual care approaches. Rather than using these, categories were derived from the respondents, using an inductive, grounded theoretical approach. Gathering data from three different agencies facilitated understanding of variations in how spiritual care is defined and implemented by the organization's culture. Finally, the social work and hospice literature repeatedly highlight the challenge for practitioners with their own diverse belief systems to work effectively with clients who also present dissimilar beliefs and values. The study's methodology elicited successful strategies in spiritual care providers' efforts to negotiate this question.

The nature of hospice care and the topic under study invited a collaborative approach. Administrators in the three agencies were apprised of the study's design, and all staff and volunteers were told about the study in staff meetings and/or in writing.

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The above methodology required that the researcher be open, pay attention, listen and watch, and systematically document the rich detailed descriptions, perceptions, interpretations and manifestations of spirituality and spiritual care.

Data Collection

Site Selection and Target Population

The three participating agencies are located on the Northeastern seaboard. Criterion-based sampling was used to select agencies for the study (Patton, 1990). Criteria for inclusion were as follows: first, the agencies were committed to the provision of spiritual care. This commitment was evident through the presence of staff who indicated they were knowledgeable of and experienced in providing spiritual care (may or may not be clergy). Second, the agencies were willing to have an external observer look at their spiritual care programs and to participate in the study. Finally, each agency served predominantly either Roman Catholic, Protestant or Jewish patients. Hospice Roman Catholic (HRC) serves primarily Roman Catholic patients; Hospice Protestant (HP) predominantly Protestant patients; and Hospice Jewish (HJ) predominantly Jewish patients. The demographic characteristics of the three participating agencies are found in Table 3.1 (following page).

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TABLE 3.1
DEMOGRAPHIC CHARACTERISTICS OF PARTICIPATING AGENCIES

Staff		**Spiritual Staff**	
●HRC	65	HRC	1 F.T., 3 P.T. + students
■HP	20	HP	.05 time
▲HJ	50	HJ	.5 time + students

Volunteers

HRC	10 spiritual, 100 regular
HP	35
HJ	100

Patients Served (1994)

HRC	95
HP	28
HJ	88

Patient Race	**HRC**		**HP**		**HJ**		**Cum. %**
White	83	88%	27	98%	62	71%	82%
Black	9	9%	0	0%	12	13%	10%
Hispanic	2	2.5%	0	0%	9	10%	5%
Other	1	.5%	1	2%	5	6%	3%
	95	100%	28	100%	88	100%	100%

Patient Religious Affiliation	**HRC**		**HP**		**HJ**		**Cum. %**
Roman Catholic	73	77%	7	25%	22	25%	48%
Protestant	9	9%	11	38%	15	17%	17%
Jewish	5	5%	2	6%	35	40%	20%
Other	5	5%	6	20%	10	11%	10%
None	2	4%	2	11%	6	7%	5%
	95	100%	28	100%	88	100%	100%

● Hospice Roman Catholic
■ Hospice Protestant
▲ Hospice Jewish

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"Protestant" religious affiliation represents a range from conservative (Pentecostal) to liberal (Unitarian). Examples of "Other" religious affiliations are Quaker and Eastern religions. The writer located four agencies that met these criteria and conducted a pilot study with one. The goals of the pilot study were: to become familiar with the work, culture and language of hospice care providers; and to develop an interview guide for staff and volunteers which was attuned to hospice work and sensitive to the issues and dynamics involved in the provision of spiritual care. In the process of achieving the goals of the pilot study, the organization and wording of the interview guides were revised twice for the purposes of clarity and ability to evoke rich and complete responses.

The target respondent populations in each agency were as follows:

1. Staff - Physicians, nurses, social workers, home health aides, clergy and volunteers;
2. Patients and their families; and
3. Selected administrators - agency founders/directors, heads of spiritual and other key departments.

The reciprocity model was utilized to gain entry to the agencies (Patton, 1990). This model of organizational entreé assumes that participants have reasons to cooperate in the research and that some mutual exchange will occur. The writer appealed to the interests of the agency administrators. In exchange for providing data, the agencies would be recognized as hospices committed to building knowledge about and developing competency in the provision of spiritual care. Participation in the study would also address agency goals or values pertaining to professional development of staff and quality

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of care. Finally, the writer promised feedback in the form of a written summary of results and an offer to meet with the interviewees. During the data gathering, respondents reported to their supervisors feelings of pleasure and affirmation derived from discussion of their work in relation to their religious, spiritual belief systems.

Sampling Procedures

Since the study's purpose is the in-depth study of a phenomenon, purposeful sampling strategies were utilized in the selection of staff, volunteers, patients and families interviewed. (Patton, 1990). Selection of staff/volunteers and their patients and families was guided by exploration of the meaning and rendering of "spiritual care." Intensity sampling strategy was employed for selection of staff and volunteers (Patton, 1990). Information - rich cases were those staff and volunteers who could clearly describe their experiences providing spiritual care. The primary selection criterion was professed knowledge of, experience in and ability to talk about providing spiritual care. In two of the three agencies the contact person individually spoke to staff and volunteers and recommended them for interviews. In the third agency the contact person sent a summary of the study to all staff and they volunteered to be interviewed.

Patients and their families served by each agency were selected based on staff/volunteer recommendation and a review of their service records. The basis for selection of patients and their families is the maximum variation sampling strategy (Patton, 1990). According to this strategy, respondents would include those for whom spiritual care is helpful or

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meaningful, those with whom spiritual care is extensively implemented or particularly problematic and those for whom it seems irrelevant.

Data Gathering Instruments

The author employed the following data gathering instruments:

1. Semi-structured interviews with staff/volunteers in each agency,
2. Semi-structured interviews with patients and their families served in each agency.
3. Review of service records of the patients interviewed,
4. Semi-structured interviews with one or two administrators in each agency,
5. Observation of selected agency meetings and care settings,
6. Archival records - agency publications, maps/charts, survey data.

A plan to interview 3 to 5 patients and their families in each agency was not fulfilled, however. Following interviews with four patients and their caregivers in one agency, only one family member was interviewed in the other two agencies. Lack of access to patients and families is discussed in "Political and Ethical Issues" in this chapter.

Interviews

Earlier studies have utilized questionnaires with hospice practitioners to identify the religious, spiritual orientations; to describe how they assess the religious, spiritual needs of their patients and families; to identify how frequently they deal with these concerns; and to describe qualities of the agencies' spiritual care programs (Highfield 1991:

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Millison & Dudley, 1990, 1992). However, none of these studies elicited descriptions of the actual spiritual care process.

The interview method avoids constrictions imposed by scaled survey questions and facilitates further exploration of respondents' answers. Personal interviews were designed to access the other person's perspective which is knowable, meaningful and able to be made explicit. The basic thrust of questions was to minimize imposition of predetermined responses. Questions were designed in a way that presupposes the respondents have something meaningful to say using their terminology, perceptions and experiences. This is important in a phenomenological study because people's language provides a powerful means to understand the phenomenon under investigation. In order to capture the world of spiritual care in hospice, the interviews were recorded and field notes were taken. These notes were detailed and concrete, describing the physical settings; what people said including quotations; the writer's own feelings and reactions; and her insights and interpretations.

Interviews with Staff and Volunteers

Before the interviews commenced, a designated staff person distributed a letter to the interviewees which introduced the researcher and described the study. It was helpful to include in this letter a brief description of the major discussion areas (not the actual questions) to be covered in the interview. It was emphasized that the respondents should not feel limited by the questions and should feel free to share what they believe is

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salient to their spiritual care work (see "Letter to Staff and Volunteer Interviewees," Appendix A). Interviews occurred at the agencies during regular working hours and most did not exceed ninety minutes. Each staff person and volunteer signed a consent form (see "Informed Consent Form – Staff and Volunteers," Appendix C). Agency procedures were followed in order to obtain permission to tape the interviews.

In designing the interview questions to explore the phenomenon of the spiritual care process, the author employed two conceptual units of analysis: meanings and practices (Lofland & Lofland, 1984). The questions elicited meanings that staff and volunteers give to the structure and process of spiritual care as well as the terms "religion" and "spirituality." The questions also elicited descriptions of the type, structure and process of spiritual care practices. The author also referred to instruments developed by Jaffe (1961), Joseph (1987), Millison & Dudley (1990, 1992) and Sheridan et. al. (1992) which addressed attitudes toward religion/spirituality in clinical practice generally and in hospice work specifically. In questioning the staff and volunteers regarding their personal religion/spirituality, the author found it helpful to include probes using language from Lehman's (1974) degrees of belief in a spiritual God and Batson & Ventis' (1982) three dimensional scale on religiosity (see "Interview with Staff and Volunteers," Appendix B).

The demographic characteristics of staff and volunteers interviewed are found in Table 3.2 (following page).

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TABLE 3.2
DEMOGRAPHIC CHARACTERISTICS OF STAFF AND VOLUNTEERS INTERVIEWED

Total Interviewed	**HRC●**		**HP■**		**HJ▲**	
Staff	12	80%	8	44%	13	62%
Volunteers	1	6%	8	44%	6	29%
Administrators	2	14%	2	12%	2	9%
	15	100%	18	100%	21	100%
Gender	**HRC**		**HP**		**HJ**	
Women	13	87%	15	83%	15	71%
Men	2	13%	3	17%	6	29%
	15	100%	18	100%	21	100%
Race	**HRC**		**HP**		**HJ**	
White	13	87%	17	94%	21	100%
Black	1	7%	0	0%	0	0%
Hispanic	0	0%	0	0%	0	0%
Asian	1	6%	0	0	0	0%
Other	0	0%	1	6%	0	0%
	15	100%	18	100%	21	100%
Marital Status	**HRC**		**HP**		**HJ**	
Married	12	80%	17	94%	12	57%
Never Married	3	20%	1	6%	4	19%
Divorced	0	0%	0	0%	4	19%
Widowed	0	0%	0	0%	1	5%
	15	100%	18	100%	21	100%
Age	**HRC**		**HP**		**HJ**	
18 - 25	0	0%	0	0%	0	0%
26 - 35	3	20%	0	0%	2	9%
36 - 45	3	20%	6	33%	3	14%
46 - 55	6	40%	5	28%	12	57%
56 - 65	3	20%	4	22%	1	5%
65 +	0	0%	3	17%	3	15%
	15	100%	18	100%	21	100%

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Professional Disciplines	HRC		HP		HJ	
Physician	1	7%	0	0%	0	0%
Nursing	4	27%	8	44%	6	29%
Social Work	1	7%	1	6%	5	24%
Clergy	5	33%	1	6%	2	9%
Aide	2	13%	0	0%	0	0%
Volunteer	1	7%	8	44%	7	33%
Other	1	6%	0	0%	1	5%
	15	100%	18	100%	21	100%

Religious Background	HRC		HP		HJ	
Roman Catholic	11	73%	7	39%	5	24%
Protestant	4	27%	9	50%	5	24%
Jewish	0	0%	1	5%	9	43%
Other	0	0%	1	5%	0	0%
None	0	0%	0	0%	2	9%
	15	100%	18	100%	21	100%

Current Religious Affiliation

	HRC		HP		HJ		Cum. %
Roman Catholic	11	73%	7	39%	2	9%	37%
Protestant	4	27%	7	39%	2	9%	24%
Jewish	0	0%	1	5%	10	49%	20%
Christian	0	0%	0	0%	2	9%	4%
Other	0	0%	2	12%	3	15%	9%
None	0	0%	1	5%	2	9%	6%
	15	100%	18	100%	21	100%	100%

● **HRC**
■ **HP**
▲ **HJ**

The number of persons of color is clearly very small in this sample (less than 10%); and less than 20% of the respondents were men. The significance of these numbers for the study is discussed in the final chapter.

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Interviews with Agency Administrators

The studies of Millison & Dudley (1990, 1992) raise several questions regarding how a hospice can facilitate or undermine the provision of spiritual care. Although an in-depth exploration of an agency's culture is beyond the scope of this study, administrators in each agency were interviewed in order to obtain a description of its spiritual care program (e.g., staffing, in-service training, service procedures) and the values, principles and assumptions associated with it (see "Interview with Agency Administrator," Appendix F).

Observation

Since this is a descriptive, exploratory study to generate hypotheses, non-systematic observation was employed (Tripodi & Epstein, 1980). Through direct, personal observation of the programs, the writer used her own experience to understand and interpret the agency's provision of spiritual care. In all observations she captured the language used and described the physical and social environments, identifying artifacts and patterns of behavior. She took notes similar to the interviews during all observations. There were no covert observations.

The author observed interdisciplinary team meetings in all three agencies, and bereavement support groups in two of the three agencies. She also observed a clergy providing spiritual care to a patient in one agency. Observation of interdisciplinary team meetings provided opportunities to understand and describe the culture of each agency in relationship to spiritual care (e.g., attitudes, patterns of behavior, procedures, issues and

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language used). Observation of bereavement support groups presented opportunities to define characteristics of spiritual care among survivors after the patient's death in a group setting. These characteristics included religious/spiritual issues and needs of the survivors and spiritual care interventions employed. Observation of the clergy providing spiritual care provided an opportunity to see how the patient and family member's religious, spiritual needs or issues were manifested (how expressed, language used) and the clergy's responses to these needs/issues. This observation also included the conditions present following provision of the care (verbal communications, body language, behaviors and actions of all people present). Except to clarify information, the writer was a non-participant observer in the interdisciplinary team meetings and the bereavement support groups. During the clergy's provision of spiritual care, she spoke with the patient's daughter to learn about the family situation.

Archival Records

Documents were reviewed based upon their relevancy to the provision of spiritual care and agency cultural factors that impinge upon it. Past and current agency publications which included employee and agency newsletters, organizational regulations, program brochures and program survey data were included in the process of data collection.

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Issues of Reliability and Validity

Since the purpose of this study is to describe the conceptual elements of the spiritual care process, it is critical that each concept be measured separately, linking its nominal and operational definitions. Principles for constructing valid and reliable data collection instruments were followed in designing and using the interview guides with respondents. Each person was presented with a standard set of mutually exclusive questions. Each question contained no more than one idea and it was made clear if experiential information, opinions, values, feelings, knowledge or demographic information was being sought. To maximize the quality of the interview findings, the questions were worded in a neutral fashion. Basic principles of interviewing were employed. Prefatory and transition statements between topics and recognition and feedback were provided as each interview proceeded. Follow-up questions clarified or further explored interviewees' responses. Probes further explored certain areas in an effort to exhaust the possible responses. These interviewing principles provided guidance for and kept the respondent invested in the interview. They also helped the researcher maintain control of the interviews.

The triangulation of methods for gathering different kinds of data from different perspectives served to maximize the data's reliability and construct validity. Key informants emerged in each agency. Although their input was valuable, the researcher used them carefully, knowing that their perspectives were limited. The writer's close involvement in the agencies and in the lives of the staff and volunteers and a few patients

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and their families was the study's greatest strength and weakness. Maintaining an analytical perspective while experiencing the program was the biggest challenge.

Political, Ethical Issues

Agencies

Regular communication through phone and letter was scrupulously maintained with each agency to keep them informed of and invested in the study. The value of openly apprising all staff and volunteers of the study's purpose also communicated the agency's commitment to the study.

Given the intensely personal and sensitive nature of the topic under study and the experiences of dying people, the voluntary nature of participation was emphasized among all subjects. All interviewees signed consent forms, and all groups gave their verbal consent prior to being observed.

Interviews with Staff and Volunteers

The introductory letter to staff and volunteers emphasized the "expert" role of the respondents in educating the researcher. Several respondents shared that this approach encouraged them to invest in a conversation about a topic which is rarely explored in depth. "Interviews are interventions" (Patton, 1990, pg. 353). The interview questions asked the staff and volunteers to share their thoughts about their religious, spiritual beliefs and values, intensely private matters for many. The interviews also asked the staff and

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volunteers to share their beliefs about and experiences with dying and death, another societal taboo. The respondents expressed comfort with and positive beliefs about death, and they "knew" that they provided spiritual care. However, a good number of them had difficulty putting their spiritual care experiences into words. Given the possibility that these interviews could raise personal issues or questions about the agency's spiritual care programs, the staff and volunteers in each agency will receive feedback in the form of a written report or a face to face meeting.

Interviews with and Observations of Patients and Families

These interviews were highly personal, taking the writer into intimate areas of persons' lives at a time when they face death – one of life's most momentous and stressful events. Therefore, the author exercised maximum professional discretion and caution in her attempts to meet patients. She accepted staff recommendations about interviewing a patient, and the patients' and families' desires and needs regarding time, people present and confidentiality were always respected. Interviews with patients and families were limited for a variety of reasons. The author's presence in each agency for a short time period (2 to 3 days for 4 to 5 weeks) and limited contact with staff during that time may have been insufficient to gain the trust of some staff. Practical issues such as time and geographical location prevented access to some patients. Finally, several patients whom staff would have referred for interviews had recently died or were too sick to participate. All patients and family members interviewed signed a consent form (see "Interview with Patients and Families," Appendix D, and "Consent Form for Patients," Appendix E).

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Data Analysis

Data Management

A typist transcribed the taped interviews which were stored in a 486 computer. The transcriptions included the author's own feelings, impressions and interpretations. Hard copies of the transcriptions and field notes were stored in files organized by agency. The writer began to analyse the data following interviews in the first agency. As the analysis proceeded, she developed and maintained an organizational system. Evolution of the organizational system was guided by the use of the two analytical units, meanings and practices, indicated above. Concentrating on these analytical units facilitated identification of the contextual dimensions of spiritual care most applicable for this study.

Cross-Case Content Analysis

A cross-case content analysis of the data was employed, using each interview and observation as a case. Logical analysis of the data within each agency identified emergent patterns and recurring themes generated by the respondents or the writer. The inductive, grounded theoretical approach to gathering, coding and categorizing interview and observational data was utilized. Analysis of the themes and relationships emerging from the categories provided by the respondents produced interpretations and possible hypotheses (Glaser & Strauss, 1967).

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The first analytical task was description. The writer reviewed the full data set for common patterns and emerging themes and developed a classification system around these themes. The data strips were coded to fit categories and subcategories in the classification system. The categories and subcategories were then tested for independence, logic and completeness. The classification system was revised until the categories and subcategories attained maximum possible meaningfulness and accuracy, and all of the data were exhausted.

The second step in analysis was interpretation. The researcher reviewed and drew interpretations from each theme in the classification system, making minor modifications in the order of the system.

Organization of the Findings

The findings could have been organized by agency or according to the dimensions of spiritual care which evolved from the analysis of meanings and practices. The writer chose the latter option for several reasons. First, this option best highlights the primary focus of the study which is the spiritual care process. Second, this option emphasizes different conceptualizations of spiritual care, an important goal of the study. Finally, this option clarifies different organizational and cultural characteristics of the agencies, a secondary focus of the study.

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The findings are presented primarily from the perspectives of staff, volunteers and administrators within the agencies, **using their own words**. There is extensive use of excerpts including quotes from the interviews in order to communicate the richness and depth of the meanings and practices of "spiritual care."

Overview of the Findings

The findings are organized into four chapters. Each chapter contains descriptive information in the form of respondent quotations, followed by interpretation of the data, and concluding with a comparative analysis across the three agencies.

Chapters 4 through 7 describe and analyse several contextual dimensions of spiritual care. Chapter 4 describes selected aspects of the culture and spiritual care programs for each of the three agencies. Chapter 5 discusses staff and volunteer motivations to work in hospice; connections between their religious/spiritual beliefs and their work with dying people; and their definitions of the terms "religion" and "spirituality." The religious, spiritual needs and resources of terminally ill patients and their families in relation to suffering, dying and death are described and analysed in Chapters 6. Chapter 7 presents the actual rendering of spiritual care. This includes principles of spiritual care, spiritual care activities and patient and family responses to spiritual care. A spiritual care process emerged from analysis of these activities. Finally, Chapter 8 summarizes this study's findings and discusses its implications for social work, including areas for further research.

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Chapter 4: Agency Culture and Spiritual Care Program

Introduction

The previous chapter introduced the purpose of this phenomenological study: to explore. describe and conceptualize the essence and structure of spiritual care provided to hospice patients and their families. Contextual dimensions related to this spiritual care process included the meaning of terms such as "religion" and "spirituality" and the religious/spiritual issues people associate with the experiences of dying and death. The agency rendering the service is another contextual dimension which was examined.

The organization culture perspective provides a revealing way to look at and understand the behavior of and within an organization. An organization's culture is comprised of: artifacts, patterns of behavior, beliefs and values and basic underlying assumptions (Ott. 1989). This perspective, which relies on descriptive, qualititative data, is an appropriate beginning approach in this exploratory study.

Although an exhaustive and comprehensive analysis of the hospice agencies' cultures is not the purpose of this project, an examination of selected aspects of each organization's culture contributes to the grounding of spiritual care in human experience, particularly in its variations across different agencies. Therefore, data describing the relevant elements of each agency's culture and spiritual care program were gathered through interviews with

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staff, volunteers and administrators; observation of meetings and care settings; and through review of agency publications. Each agency's history, its values, the structure of its spiritual care program and people's attitudes toward this program follow. The agencies are labeled according to the primary religious affiliation of the people served. The chapter concludes with a comparative analysis of these dimensions across the three agencies.

Hospice Roman Catholic (HRC)

History

This freestanding hospice, established in 1982, is located in a suburb and primarily serves a white, Roman Catholic population. In 1990 it opened the first residential hospice in its state which provides 24 hour care for eight people with no primary caregiver. The balance of the 95 patients is served in the home by approximately 65 staff. Organizational "stories" tell the history of an organization, perceived to be accurate (Wilkins, 1983). The stories reflect organizational beliefs and values (Martin & Siehl, 1983). "Heroes" are the leading actors in organizational stories. They personify the values and reinforce and maintain the culture by setting standards of behavior and providing performance role models (Ott, 1989). Some organizations develop "sagas" or "legends" which build members' allegiance, commitment and emotional investment. Clark (1970) identifies a saga as something between an ideology and a religion. "An organizational saga turns an organization into a community, even a cult." (p.235).

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The culture of Hospice Roman Catholic (HRC) embodies several of the organizational characteristics described above. The agency's "story," well-known in the community, involves its two founders, a nurse and a Roman Catholic priest. Troubled by the poor treatment of dying people in a hospital where they were employed, these "rebels blazed a new trail," left the hospital and for a time provided care to dying patients and their families on a voluntary basis. These "heroes" consciously communicate and personify the agency's values and standards of behavior. The agency's "saga," developed over the years, attracts and maintains employees and volunteers who make a deep emotional commitment to this "family."

Values

> Shared beliefs, values...are central to organizational culture. They provide the justification for why people and organizations behave as they do. It is virtually impossible to understand the meaning and importance of artifacts and patterns of human behavior... without knowing the beliefs and values that shape and drive them (Ott, 1989, p.41).

The agency's central beliefs and values are conveyed in its publications in which the agency uses symbols to great effect.

> Symbols are signs that connote meanings greater than themselves...and cause people to associate conscious or unconscious ideas that...endow them with their deeper, fuller and often emotion-evoking meaning (Ott, 1989, p.21).

HRC's symbol, a burning candle in the window, is found in every publication. The burning candle or the flame is a powerful religious and/or spiritual symbol which conveys hope in the midst of overwhelming darkness. It is also an apt metaphor for the founders'

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saga - an effort against almost overwhelming odds to serve the most vulnerable and needy people. The agency's newsletter is named "Flame." One of the founders writes an article in each issue. In one issue the priest refers to:

> ...the urgent mission of hospice...those alone – suffering and dying...In those patients and families we have discovered the living presence of God. It is He who cried to us to intervene - to bring comfort and love at the most critical time (Flame, 1993).

Clearly, a strong **mission** orientation, drawing on Christian theology and symbolism, pervades this agency. The priest further explains:

> We built the agency on a sense of mission. The ultimate spiritual value is compassion...So this organization is built basically on the value of compassion. Compassion means the willingness to suffer with those who suffer, to feel their pain and to be a part of it...This is what has called us to this work.

The administrators personify this mission through their active involvement in all aspects of the agency's work including patient visitation. One administrator explained how they approach their work with a profound sense of humility:

> The thing that drives this organization...is that there's nobody on top who is not willing to do the most menial of tasks in order to ensure the comfort of the patient...We have never lost that sense of touching skin...It's extremely important to be in the trenches with the people that you're caring for.

Given this religious impulse, the spiritual component of care is the centerpiece around which all services revolve.

> Right from the beginning there was no doubt in our minds that we would have a strong spiritual component... All of the spiritual issues in peoples' lives were absolutely integrated into every decision we've ever made.

> The spiritual part which motivates all the disciplines toward their mission can't be diluted because it's the roots of everybody who's doing their own particular work.

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The agency "...stands apart from its peers. It places a unique emphasis on spiritual values" (Agency Brochure, 1993).

Finally, the directors view the staff and volunteers as "family," implying a level of commitment which goes beyond most jobs. "Nearly 200 people are part of the immediate family" (Brochure, 1993). The administration intentionally seeks "spiritually motivated" people.

> In the interview I try to determine if they're spiritually motivated. Hospice is a spiritual movement and if you don't feel spiritual, think spiritual, if you are opposed to spirituality, this isn't for those people.

Of the 13 people interviewed for this study, 10 had known the founders personally or by reputation. They had all heard the agency's "saga," and had made a deep emotional investment in the agency.

> People have come here because they've heard of us, been attracted to us...They recognized there was a difference in how we do things...The people that have come here for a job haven't stayed. The people who come here want to be a part of something bigger than themselves and want to touch a part of people and have themselves touched in a part professionally they have never been touched before.

Structure of Spiritual Care Program

Believing it would most appropriately reflect the agency's dedication to its mission, in 1990 the founders created a separate department for spiritual care and hired a clergy to oversee the program. A full time Spiritual Care Coordinator administers this department which is equal in status to nursing and social services and is staffed by three part-time

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clergy and approximately 10 spiritual volunteers. These staff and volunteers are trained by the Coordinator and are assigned only to this department. Volunteers meet monthly with the Coordinator for ongoing education and support. Each spiritual staff person serves 10 to 12 patients and families in the home.

The spiritual department is highly visible and active within the interdisciplinary team in all phases of service provision. One director described the importance of spiritual staff relative to the team:

> The spiritual department feels a genuine support by the administration because we place such a high expectation on them...I will not begin a meeting without a spiritual staff present...I lean heavily on the spiritual department to show their performance because I don't want them to be diluted.

A spiritual staff person visits all new referrals and completes a spiritual assessment following initial visits by a nurse, then a social worker (See "Spiritual Assessment – Hospice Roman Catholic," Appendix G). In order to avoid premature refusal of spiritual care by patients, the agency presents spiritual care as "support services." A spiritual volunteer explained:

> We try very hard to explain that we are not just religious but spiritual support which is very difficult to do with other people - they don't know what the difference is...I think it's as necessary as any other kind of care...Of all times in your life, this is when you need it most.

A spiritual staff person attends all team meetings, provides a separate report and spiritual goals when appropriate for each patient/family unit. The department files its own forms in a separate section in patient records. It is widely understood within the agency that the

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Spiritual Department has primary responsibility for "long-term counseling." The Coordinator of Social Services explained:

> We social workers will do a lot of **concrete** services; but because we have such a well-developed spiritual department here, they really assume responsibility for long-term or ongoing counseling. Anything that we see requiring long-term work, we refer to the spiritual department.

Bereavement services are within the Spiritual Department and include: child, adolescent and adult support groups; a community-based grief seminar series; and individual counseling.

There are no formal staff support groups. The administration believes the memorial services perform this function. The Spiritual Care Coordinator leads an annual memorial service for survivors, staff and volunteers. When a large number of patients die over a short period of time, the agency offers additional services for staff and volunteers. At these services names of deceased people are read, followed by time for verbal sharing and meditation or prayer. One director described the critical, supportive role these services play in care providers' lives:

> A nurse could maybe lose 20 patients in a quarter, and that's a lot of lives to go through...People that need to be there are there...That is the most therapeutic experience I think that anyone goes through...It's what ties us in spiritually...needed in order for us to continue to go on.

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Attitudes Toward Spiritual Care Program

The writer interviewed staff and volunteers recommended by the Spiritual Care Coordinator. Among the 13 respondents, five are within the Spiritual Department. Spiritual staff and volunteers expressed confidence in their abilities and used fairly uniform language when discussing their work. Respondents outside the Spiritual Department expressed positive attitudes toward the program, viewing the spiritual staff and the administration as spiritual leaders and resources. They did not appear to feel excluded from this province of care but, rather, seemed pleased and perhaps relieved that others more qualified were available for this service.

Believing the spiritual care program to be "on the cutting edge" of the field, the administration and the Spiritual Care Coordinator express "...sincere faith in the rightness of what they are doing" (Brochure, 1993).

> It's what sets us apart; no one has the spiritual department we have...We could paper Radio City with the letters we get from people that survived because of our spiritual program.

The Spiritual Care Coordinator and the administration only wished that more patients and families were open to spiritual care and that all staff could receive spiritual training.

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Hospice Protestant (HP)

History

In 1978, a group of concerned citizens - physicians, social workers, nurses and community leaders - conducted a demographic study in their county which revealed the lack of alternatives to the hospital for dying people. Clergy and members of the religious communities were actively involved in these early efforts. In 1987, an autonomous agency was established within the area's medical center.

Located in a rural area with small towns, the population is historically primarily Protestant, and the patient census is more Protestant (38%) than any other single religious affiliation. However, the population has increasingly diversified with 20% currently reporting religious affiliations outside Judaeo Christianity. The current administration has been in charge for the past six years. Approximately 20 staff serve an average census of 28 patients and families in their homes. According to the Chief Executive Officer:

> Spirituality was a very strong piece of the history because of who the people were involved in it...I think there was always a sense of spirituality as opposed to religion. These were not people who considered themselves church-goers, but very much believed in a different way of taking care of people and the opportunity to give to people for the journeying, without labeling it spirituality.

Values

The religious/spiritual backgrounds of the patients and the employees and volunteers are diverse. Knowledge of these diverse backgrounds and the ability to serve the people are

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highly valued. The expression of and respect for diverse backgrounds and experiences became evident through interviews and team meetings when varied terminology was used in reference to spiritual care. This diversity is apparent in a memorial service bulletin which includes references to Christianity and a prayer from a Rosh Hashanah service. A Native American prayer is on the back of the bulletin. The symbol of the flame - "a burning fire," "the candle of our life" – provides a unifying theme throughout the service.

Competence in one's professional discipline and cooperative working relationships across disciplines are also valued. All staff are located in close quarters within the medical center which affords easy communication and close interdisciplinary team work. This has developed into a strong, informal care and support network which is consciously nurtured by its members.

> Respect for one another's belief systems and concern for each other – unique in my work experience. There are times you'll have difficult patients; we share those patients. It's such a stressful job that you have to keep an eye out for each other.

Finally, the administration and some board members continually affirm the agency's autonomy within the medical center. They point to the spiritual component of care as the defining element which makes the agency's health care unique. A physician and board member explained:

> It's (spirituality) what differentiates hospice from hospital care, general nursing home care and from home health...I feel that what I have to do is make sure the spiritual emphasis is preserved.

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Structure of Spiritual Care Program

The administration explained that spiritual care is integrated throughout the agency rather than housed in a separate department. Although no person is held responsible for spiritual care, a Protestant minister who is the full time Chaplain for the medical center attends interdisciplinary team meetings, visits hospice patients when they are hospitalized and in the home upon request. He meets with new volunteers in a training session and is available to staff for consultation. He also leads the agency's annual memorial service.

The administration considers all staff and volunteers "spiritual care providers." A nurse and social worker team visits new referrals and the social worker addresses religious, spiritual issues in her psychosocial assessment (See "Spiritual Assessment – Hospice Protestant," Appendix H). Any member of the team may raise spiritual/religious issues in team meetings. During the meeting the writer attended, these concerns were raised by various team members for most patients and their families. Spiritual care is documented in nursing or social work progress notes, depending on who provides the care. No formal spiritual training is offered to staff. However, the Chaplain provides a meditation at the beginning of team meetings and a particular staff person is asked sometimes to provide a spiritual exercise at the end of these meetings.

Spiritual care is also integrated within bereavement services which are coordinated by the Social Work and Counseling Department and provided by social workers and nurses. In addition to mailings and individual visits with survivors, support groups for children,

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adolescents and adults are provided. During the writer's observation of a support group for adults, religious, spiritual issues were raised and discussed frequently by the group members.

Attitudes Toward Spiritual Care Program

All staff received a written explanation of this study's purpose and approximately three quarters eventually volunteered to be interviewed. Some who had not initially volunteered later did so after hearing of others' experiences. Most of the respondents expressed positive attitudes toward the spiritual care program, pointing first, to its integration within the agency's operation.

> Staff have developed to the point that it's integrated into everything they do...It's a part of our orientation, of psychosocial assessments, of team meetings, of the care plan, although it may not be called spirituality.

> It's something that's always addressed. As far as establishing what the goals are for the patient and family and what's important to them, I think we address that and help them as much as they want.

Second, many believed the spiritual care program was enhanced by diversity in staff backgrounds and their respect for and support of one another.

> This agency is probably the most open, accepting and expressive in their communication of any group of people that I have ever met. Paper work includes spiritual care but it's not boxed out and isolated and easily found except for that initial spiritual assessment. There's a tremendous acceptance of where people are. No judgement of religious beliefs.

A board member described the staff:

> I've never met a more dedicated group of people who really seem to care about others... And it crosses over all segments of religion.

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Several felt that the "presence of spirituality" created a positive work environment.

> I think although it's never spoken, you know it's there...There's a feeling within the organization, the Board, that spirituality plays an important part of total hospice care. Volunteers are made to feel a part of the team.There is a spiritual feeling when you come in here...They (staff) have a tremendous sense of the emotional, psychological and spiritual needs of patients.

A third reason why people feel good about the spiritual care program is the spiritual leadership they receive from the Chaplain and administrators.

> Staff respect him (chaplain); for some, the first healthy, respectful relationship with a clergyperson.

> He's an exceptional chaplain. He seems to be good at knowing where people are at or he's smart enough to show that he's not sure. He doesn't come on strong with people who aren't religious...Yet he can get right into the religious thing when needed.

> (An administrator) is powerfully up front with where she is. I've seen her moved by a person's pain. She lives her own spirituality.

Finally, a few felt that an individualized approach to spiritual care, relying on the resources of each staff person or volunteer rather than a uniform, system wide approach, was a strength.

> I think everybody does it in an individual manner according to their own spiritual beliefs and connection. Most of us are comfortable with it. It's very loose. I don't think we ever talk about the spiritual care we gave to so and so, but it's definitely there. It's just so difficult to put into words...As far as our own spiritual care, it's done on an individual basis.

Several people expressed ambivalent attitudes toward the agency's spiritual care program. At times it is given only "lip service," or it is so understated that, "I think we do it without knowing it." Feelings of inadequacy regarding their abilities and the need for "spiritual training" were expressed by several.

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> A lot (of staff) feel uncomfortable; some bring in clergy as soon as possible. We're all shooting in the dark; don't know what's expected of us. No one knows how to present it to us or to the patients and families. The agency should give more guidance. I think it would be helpful if it was part of the orientation. Certain common denominators come up and there are certain responses that seem to help people to start talking about things on their mind. I learned by talking with nurses, social workers, and by trial and error experience.

A board member discussed the challenge involved in spiritual training.

> You might get some people who feel as though you're becoming a religious organization and resent that. It would have to be done very carefully so as not to step on someone's toes.

Administrators believe the spiritual care program has improved in terms of staff recognizing its relevance and feeling more comfortable with it.

> What I see today is that it's a very integral part of what we do. Everybody understands what we mean when we say it...I think it's something you need to keep raising consciousness of...within team meetings, sometimes informally in conversations.

Rather than any change, the current program requires continuous staff and volunteer support and education. The Executive Director and the Director of Clinical Services explained:

> Don't have to change anything. But we need to keep vigilant, especially as we orient new people; must give them information to make them comfortable. Must maintain level of comfort in talking about it. Respect diversity but also keep common ground.

> I don't see any need for change as far as our philosophy and mission. I think we still have a lot of growing to do...Our ability to maintain quality of care and the spiritual aspect is a challenge right now as we're growing.

According to the Executive Director, educating the religious community about hospice, particularly spiritual care, is also critical to maintaining a strong program.

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> A goal of the strategic plan was that the local churches would not see us as competition but complementary to what they do. This is a church-oriented community. How clergy viewed us was critical to our success...The church sees us now as part of their outreach mission.

The two administrators expressed strong beliefs about the role of spiritual care, stating that the future existence of hospice within health care (specifically within the medical center) is dependent on nurturing and maintaining the spiritual care component.

> Managed care is pushing people into hospice. The danger is going to be that we unbundle the program, giving them individual services instead of (the) whole package...My battle is to preserve what we have in hospice.

> The psychosocial and spiritual aspects are going to be more of a challenge because they're not viewed the same way as physical care; they're not concrete...Hospice is going to have to show how the things that we do...impact on the care outcomes because everything is becoming so outcome-oriented. How does spiritual care impact on patients? That's difficult because it's not quantifiable.

Hospice Jewish (HJ)

History

Founded in 1988 by community leaders and personnel within a well-established, urban medical center, this hospice is located in a major metropolitan area. In addition to home care services, a unit for eight patients is located within the medical center. People are admitted to this in-patient unit (IPU) for brief periods to make changes in pain management, to treat specific symptoms or to provide a respite for families. Approximately 50 staff serve an average census of 88 patients. The medical center was originally established to serve the area's Jewish community. Although non-sectarian, the

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hospice currently serves more people who identify themselves as Jewish (40%) than any other single religious affiliation. The current executive director arrived in 1994.

How to provide spiritual care sensitive to Jews and non-Jews received serious attention during the agency's formation. An administrator who was involved in the agency's founding explained:

> It (spiritual care) came up frequently in discussions of staffing and mission... We argued about wording in statements and policies and brochures... Religious symbols and spiritual comfort came up over and over.

For example, there were many intense discussions of how to make the design and decoration of the IPU non-threatening and comfortable for holocaust survivors. The hospice was also meant to be "religiously inclusive," according to the executive director.

> There was a very intense spiritual commitment made in the very founding of the hospice...From the beginning it was assumed to have a spiritual integrity and meaning that was intended to be religiously inclusive.

Values

This agency's dual commitments to the Jewish community and to the diverse non-Jewish groups contiguous to the medical center is highly valued by the service providers. A strong commitment to professional development is also evident. All staff are expected to attend regularly scheduled training sessions which at times include information on different religions. They are also encouraged to participate in and present at professional conferences. Finally, the agency encourages ongoing assessment of their own beliefs and

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values to further their knowledge of and sensitivity to people's needs. An administrator explained:

> Part of the orientation and ongoing education and supervision of staff include looking at their own presumptions; the effect of their own experiences and their own feelings of the value of life...I'd like to see a little more time spent on helping our staff understand the values and practices of those religions that we're not so knowledgeable of.

Despite periodic, heated discussions in interdisciplinary team meetings, mutual respect, regardless of one's education or position, is evident. The staff, particularly nurses and social workers, have used their cramped office quarters within the medical center to develop caring, supportive relationships. This informal communication and support network is reinforced by the agency's provision of staff support groups.

Finally, several staff and the administration expressed the critical need to remain autonomous within the medical center and to educate hospital personnel about the hospice philosophy of care.

Structure of Spiritual Care Program

The Pastoral Care Coordinator is a half time rabbi who was hired when the agency opened. The Coordinator forms a separate department, but the administration considers all staff "spiritual care providers," and the clergy's role is to coordinate spiritual care for patients and families in their homes and on the IPU. From the beginning he was also expected to cultivate and maintain relationships with clergy within the medical center and in the surrounding communities to ensure appropriate care. An administrator explained:

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> (There were) incredibly intense, long discussions about (the) religious background of (the) hospice chaplain and ability to collaborate with ministers and priests of other religious denominations.

Although there is a separate department, spiritual care services have neither a separate section in patient records, nor a separate report in team meetings. The Coordinator attends all team meetings, but any team member may, and in about half the cases this writer observed, did raise the topic. Social workers, responsible for "psychosocial counseling," complete a spiritual assessment on all new referrals (See "Spiritual Assessment – Hospice Jewish," Appendix I). The Pastoral Care Coordinator sends a letter to all new home care patients and will, upon request, complete a more in-depth spiritual assessment and provide "counseling" (See "Spiritual Assessment – Hospice Jewish," Appendix J). He visits all patients and leads religious celebrations on the IPU. No ongoing spiritual training is provided to staff or volunteers. However, the Pastoral Care Coordinator leads a volunteer training session and organizes an annual staff in-service presented by a well-known religious/spiritual leader. The agency provides monthly support groups for home care staff, in-patient staff and supervisors. Attendance at these groups is mandatory.

Bereavement services are located within the Social Work Department and are provided by a half time coordinator and five trained volunteers. Services include: phone contact, mailings, individual short term counseling and support groups. The Bereavement Coordinator explained how religious or spiritual issues arise in these groups:

> Usually brought up by group members. We're dealing with ultimate issues of meaning, connection: primary existential issues - issues of the spirit...This is

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> not a place to proselytize, but to hear feelings, experiences. I make it safe to be where they are. This is the same for spiritual and other issues.

Attitudes toward Spiritual Care Program

Staff and volunteers were recommended for interviews by the Coordinators of Pastoral Care and Volunteers respectively. A majority of the respondents expressed positive attitudes towards their spiritual care program. Many of these attributed the program's strength to the rich diversity of backgrounds and skills among the staff and volunteers.

> We have different styles. I think that's good; a very healthy approach because not only are patients helped but we are all helped by each other.

> This agency is exceptionally aware of spiritual care. There is acceptance, openness to this realm; interest, curiosity...Not within any particular tradition - western tradition and therapeutic touch, use of massage.

Several staff complimented each others' abilities.

> I don't think the social workers are afraid or embarrassed to bring up issues of spirituality on their own. Some of the nurses provide both spiritual and medical comfort rather than just medical comfort.

> The social workers here are really interested in religion. Social work sees religion as one of the many coping mechanisms that individuals have who are dying. That's the reason why they call us (clergy) to be involved with the scene.

> The good thing about the hospice and the team is so many of the nurses are willing to treat spiritually while doing their nursing.

Volunteers spoke highly of the Pastoral Care Coordinator's availability and provision of spiritual care regardless of the religious backgrounds of the patients.

> We provide religious people for whatever religion they have. (Chaplain) is a wonderful man, a mentsch.

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Finally, respondents described ways that spiritual care is integrated into all levels of the agency's operation, including hiring and training people. A nurse amd an administrator explained:

> I think it's from the top all the way down. It's really how you hire somebody. It's part of when we do a group interview.
>
> We try to have at least one in-service a year that's spiritually focused. For example, an in-service focused on...articulating our own spiritual philosophy. When I interview people, I ask how their spiritual philosophy impacts on their practice.

A social worker and a clergy voiced the belief among many who expressed positive attitudes but also felt that spiritual care could be improved.

> It's not as important as it should be, but it's becoming more important...It definitely has a major presence. We do OK; we can do better.
>
> We could do a lot more...When we have a patient who is a great model of spirituality, our team will talk about that. It's rare...Sometimes I feel it's difficult to get in and discuss spiritual issues.

Ambivalent or negative attitudes, focused primarily on the Spiritual Care Coordinator, were expressed by a few. Some criticized the Coordinator for a lack of spiritual leadership among the staff and a tendency to focus only on religious issues with patients. A social worker and a nurse described their concerns.

> I don't think we have good spiritual leadership. (Coordinator) doesn't work with staff on how to bring up spiritual issues. I know he's religious, but no sense of spirituality in him...He can't provide spiritual guidance to staff or people not religiously observant.
>
> I feel that our pastoral care is more religious than spiritual. I would like it to be the other way around. Doesn't exclude spirituality but he doesn't really appreciate it or exude it or illicit it from patients.

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One person criticized the agency for a lack of spiritual training but felt good about various staff persons' abilities.

> We don't get particular training on it. I think there are people here who have very strong spiritual beliefs of their own and they bring them to the agency, so there is an incorporation of spirituality in how we function and interact sometimes, but not always.

A supervisor and the administrators analyzed the agency's spiritual care program and discussed suggestions for its improvement. One supervisor pointed out good and bad points of the agency's approach to spiritual care which "splits off religion from spirituality, placing religion in the Chaplain's domain and spirituality in no person's province."

> Spiritual care comes from the heart: Spiritual connectedness flows through desire/humanness...(But we're) not always clear on the possibility of being there in a spiritual way; unsure of, uncomfortable with boundaries.

This supervisor recommended that spiritual care be "highlighted, made public" in supervision and in team meetings, and staff "should be reinforced for doing this kind of work." Working with the Pastoral Care Coordinator to increase involvement of clergy in the community was also an administrative concern.

> It's real hard to find chaplains, religious leaders, who are comfortable enough with death and dying issues to be effective in their counseling with patients and families...That's an area in our program that we'd like to build.

The Chief Executive Officer offered a reconceptualization of spiritual care within hospice. This reconceptualization derives from the need to place spiritual - and all types of hospice care - within a framework more inclusive than the medical, health care model of service. He called this larger framework:

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> ...humanness...One of the places where hospice started was in asserting the idea that dying was a human process not a medical problem.

Viewing dying as a medical problem invites a "problem-identified, intervention-oriented" approach to care. However,

> Spirituality deals with the ongoing inner process through which a person finds meaning in what is happening in their lives.

The intervention-oriented model of health care creates the situation where:

> That basic core grappling for meaning and value gets sucked into different problems and...is dealt with primarily fragmented and not consistently and organically as it needs to be done.
>
> I therefore see the spiritual care of hospice needing much more focus not on problems, but on that inner process of the person to find meaning and value in their experience.
>
> Rather than an intervention model, there needs to be an accompanying, a going-with someone on this part of their life journey, a paying attention to what is happening rather than trying to make something happen or fixing something.
>
> It therefore cannot just be limited to pastoral care staff, however that is defined; but really is sort of the overarching context in which all care is given and supported...

Cross-Agency Analysis

How one looks at an organization's culture largely determines what it is (Ott, 1989). It is important to remember that this study solely examined elements of the agencies' cultures **related to spiritual care**, and the informants were asked to refer only to this aspect of their organizations.

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This examination of three agency spiritual care cultures identified several broad similarities. First, they all affirm the spiritual component of care, calling it "the roots of everything," "the overarching context of all care" and that which makes hospice distinctive from other types of health care. Second, staff clergy in all three agencies attend and participate in team meetings where religious, spiritual issues are frequently discussed. Finally, many staff and volunteers in the agencies view agency leaders as resources for spiritual and other types of support.

Comparative analysis of the agencies' cultures produced differences in their histories (including the religious, spiritual orientations of personnel), values and the types of authority utilized. These differences are apparent in a typology of spiritual care program structures. The analysis concludes with a description of the distinctive qualities of each spiritual care culture.

History

Since it is a newcomer to the health care field, there is little in the literature about hospice as an organization. However, two studies looked at the evolution of hospice as an organization within the health care system (Paradis and Cummings, 1986; Hecht and Moser, 1991). Masterson-Allen et. al. (1987) examined staff turnover in hospice as a function of organizational growth.

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In this study, the writer found that two organizational elements – auspices and significant publics – influenced the formation and brief history of each agency. An organization's auspices are institutional arrangements that govern what that organization does. They are often sponsors of the agency's services. Significant publics are key constituencies to whom an organization is accountable and upon which it depends for organizational stability. An organization has internal and external significant publics (Kurzman, 1992).

These hospices all have private, non-profit and non-sectarian auspices. However, HRC is a freestanding, singular organization, and HP and HJ are institutionally affiliated. The agencies have similar significant publics internally - board members, staff, volunteers and patients and their families. They also have several external constituencies in common – health care institutions, physicians, government agencies and licensing institutions. However, these constituencies differ in their level of diversity, including religious affiliation, and in their level of complexity.

HRC's publics are historically rather uniform - Roman Catholic churches, hospitals and nursing homes - and they are located in neighborhoods populated predominantly by white, Euro-American, Roman Catholic people. The agency's internal publics reflect this uniformity. Approximately three quarters of the workers, patients and families are Roman Catholic. The external and internal publics in HP and HJ are much more diverse and complex. HP is located in a rural area containing small towns which were historically

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"church oriented" and dominated by white Protestants. The population has become much more diverse with the arrival of new corporate businesses and people who commute to an urban center. The current patient census shows that 38% are Protesant, 25% are Roman Catholic and the remaining third report another or no religious affiliation. The workers' affiliations are similarly diverse except that fewer report no affiliation. HJ serves a cosmopolitan, urban center with its diverse publics. Forty percent of its patients are Jewish, 25% are Roman Catholic, 17% are Protestant and the remainder (18%) report another or no affiliation. Among the workers, 50% are Jewish, an equal number (10%) are Roman Catholic or Protestant and the remaining third report another or no affiliation. Although the constituencies of HP and HJ are both diverse, there is an important difference. HP and its medical center have no historical commitment to any particular ethnic or religious group, while the medical center of HJ was established by, is financially supported in part by and is committed first to serving the area's Jewish community. In addition to the diverse external publics, the institutional affiliations of HP and HJ create multiple internal constituencies. Working relationships are particularly complex among those who are involved in both the hospice and the medical center - board members, Chief Executive Officers of the hospices and some staff such as physicians. The significant public which presents perhaps the greatest organizational challenge is the patient who is served in both organizations. Table 4.1 (following page) summarizes a cross-agency comparison of worker, patient and family religious, spiritual orientations. In all but one category, HRC has the least diversity, HJ the greatest diversity and HP falls in between the two.

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Table 4.1

Religious, Spiritual Orientations of Workers, Patients and Families

		Level of Diversity		
		Low	**Medium**	**High**
1.	Worker Change in Affiliation	HRC	HP	HJ
2.	Variation among Workers	HRC	HP	HJ
3.	Variation among Patients/Families	HRC	HJ	HP
4.	Variation between Workers and Patients/families	HRC	HP	HJ

Values

Organizational values have been shaped to varying degrees by the auspices, significant publics and leadership of each agency. The values of HRC were established by its leaders and reflect their religious, mission orientation. These "heroes" have made spiritual care their top priority and they recruit "spiritually motivated" members to join their "family." The values of HP and HJ reflect the diverse constituencies within their institutions and communities. Both agencies value: diversity in work skills and in religious, spiritual backgrounds; professional development; mutual respect and support of one another; and autonomy within their institutions.

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This analysis of the agencies' values suggests different levels of "professionalism" and "professionalization." Professionalism refers to an ideology, built on a set of social-psychological attitudes, beliefs and values, and associated with aspiration of professional status (Reeser & Epstein, 1990). These beliefs and values include political neutrality, restrained dignified decorum or control of one's emotions, and superiority of the worker versus the client definition of problems (Epstein, 1969). Professionalization represents the social-structural process of incorporating this ideology within an organization. Reeser & Epstein measured organizational professionalization by the number of professionals in the organization, the training required for specific jobs, the level of activity in professional associations and ongoing knowledge development.

The levels of professionalism and professionalization vary in the agencies according to their values, their professional decorum and the training and responsibilities of social workers. HP and HJ more strongly espouse the values of professionalism and demonstrate greater organizational professionalization than HRC. These two agencies hire Master's level social workers who are responsible for "psychosocial counseling." HRC is more likely to hire BSW's who are responsible for "concrete" financial and community services. Although HP and HJ articulate similar professional values, workers in HP usually showed emotional restraint while staff in HJ expressed lively emotions and engaged in some strong disagreements. HJ also has greater expectations for staff participation in professional associations and conferences than HP.

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The stated purpose of professionalism is the reduction of influence on one's work of gender, race, political affiliation and religion. Using the concept of "latent social identities" (Gouldner, 1958), Reeser and Epstein (1990) found that a professional's personal background and affiliations, although ignored by the organization, remain latent and influence the person's level of social activism.

In an effort to determine the latent role that religion plays in the agencies, the writer examined workers' references to religion or spirituality in general and to the religious backgrounds of their patients. Respondents in HRC frequently used the terms "religious" and "spiritual" in reference to their work, and this aspect of care was very evident in their team meetings. Since the majority of their clients are Roman Catholic, they often referred to this religion when describing patient concerns and their spiritual care activities. In contrast, this language was much less evident in the workers' language in HP. When it appeared, staff used the term "spiritual," and "religion" was rarely heard in meetings. Furthermore, workers rarely referred to the religious backgrounds of patients in describing their spiritual care activities. In HJ, workers used both terms, drew more distinctions between "religion" and "spirituality" than in HRC and HP, and frequently referred to the specific religious/spiritual backgrounds of their patients. Clearly, "religion" is more latent in HP than in HRC and HJ. The differences can be attributed to the level of diversity in religious/spiritual backgrounds and the histories of the agencies. Although HP still serves more Protestants than any other religious affiliation, their patient census has become varied to the point that workers appear to espouse an ecumenical orientation

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to their spiritual care work. Furthermore, this agency's history has neither a religious impulse like HRC, nor a tradition of serving a particular religious/ethnic group like HJ.

Types of Authority

Each agency was examined according to the type of authority it utilizes. Weber (1949) developed three pure types of legitimate authority, based on his "ideal type theory."

> An ideal type is formed by the one-sided accentuation of one or more points of view and by the synthesis of a great many diffuse, discrete, more or less present and occasionally absent concrete individual phenomena which are arranged according to those one-sided emphasized viewpoints into a unified analytical construct (p.60).

The result of "ideal type analysis" is that each organization is presented in "artificial simplicity of ideal types as they could at best but seldom be found in history" (Weber, 1958, p.98). Ideal type was not a criterion for selection of the agencies in this study. However, a comparison of the types of authority used in each agency provided further clarification of their distinctive spiritual care cultures.

Weber (1947) identified legal, charismatic and traditional types of legitimate authority. Legal has also been called bureaucratic, or professional authority. It rests upon the rational belief in the legality of normative rules which forms an impersonal order or system based on the principle of hierarchy. The person in authority is elevated by the system to an "office." Members are loyal to the impersonal system, not the person in authority. They are recruited and occupy "spheres of competence" based on their specific

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training and education. Decision-making is based on the legal rules, norms and procedures which are applicable across different situations. Charismatic authority:

> ...constitutes a call...a 'mission' or a 'spiritual duty'...It is the duty of those who have been called to a charismatic mission to recognize its quality and to act accordingly (Weber, 1947, p.359, 362).

The charismatic leader makes decisions for her organization in fulfillment of her duty. The basis of member recruitment is the leader's personal charisma, and "...disciples or followers live primarily in a communistic relationship with their leader" (p.361). Unlike legal authority, there are no formal rules and no established positions, roles or responsibilities among the members. An organization using traditional authority also has no clear spheres of competence or specific training required of its members. However, the sanctity of order as handed down from the past, and not the leader's charisma is the basis for the leader's authority and decision-making. Members are loyal to the leader, or "chief," not an impersonal system. This personal loyalty is cultivated through common education and socialization experiences over time.

The founders of HRC responded to God's call to serve the terminally ill and their leadership fulfills this spiritual duty. Members have been drawn to the "family" by the charisma of its leaders. According to Weber (1947), charismatic authority cannot remain stable after the founding of an organization and it gives way to the forces of routinization. becoming legal or traditional or a combination of both. HRC has assumed some visible characteristics of the legal or professional authority type. Responding to the need for economic and job security of its members and the desire for legitimization as a licensed

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health care provider, the leaders created departments, including a spiritual care department, and work positions and roles based on levels of education. While creating these "trappings of a bureaucracy," the leaders express concerns for the agency's growth and loss of "the family." Weber (1947) points out that charismatic authority is strongly opposed to legal and traditional authority since both represent everyday routine control of action. Charisma is outside of and repudiates everyday routine. The agency's founders repudiate a number of the principles of a bureaucracy. Their discomfort with a hierarchy is evident in the agency's flat table of organization. They are involved in all aspects of the agency, including visitation of patients. This involvement extends to making decisions at all levels, at times overriding the decisions of department heads. Their spiritual mission, and not an impersonal system, remains their guiding principle - and the source of their authority for as long as the members believe in them. These leaders embody some characteristics of "servant leaders" – those who want to serve first and to lead second (Greenleaf, 1977). The primary talent of the servant leader is the ability to "conceptualize – to know the unknowable which is partly a matter of faith" and to passionately communicate one's faith in the work (p. 32-34).

HP consistently demonstrates the use of legal or professional authority. All decision-making, including selection of its leaders, is based upon an impersonal system of established norms, rules and procedures. Members are recruited and serve in spheres of competence on the basis of their specific education or training.

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HJ does not easily fit any one of the three ideal types of authority but demonstrates aspects of each. Characteristics of legal or professional authority are most evident in its everyday operations. These include written policies and procedures, professional rules and norms and a hierarchical system of labor with spheres of competence based on levels of training and education. Stepping away from the daily operation and looking at the agency embedded within the medical center with its own particular history, one can see aspects of traditional authority operating. The medical center's original commitment to serve the Jewish community introduces a particular religious/ethnic tradition which guided decision-making in the establishment of the hospice. This is especially evident in the selection of the Pastoral Care Coordinator and in the design of the in-patient unit where scrupulous attention was paid to the particular needs of terminally ill holocaust survivors. As a member in this organization, one is educated about and socialized in the Jewish culture and communal service system within the medical center and surrounding community. Finally, this agency's current executive introduces aspects of charismatic authority into the organization. An ordained clergy, he entered hospice work in response to a "calling." He is actively involved in the national hospice organization and has been called the "pied piper" of the hospice movement. He is articulating a vision for the agency, calling for a return to the original philosophy of hospice which views dying as a human process, not a medical problem.

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Structures of Spiritual Programs

A typology of three different structures of spiritual care emerged from this comparative analysis. The typology, shown in Table 4.2 positions each agency in a matrix identifying the level of formal identification of its program within the agency; and the level of division of labor that its program represents within the agency. HRC has the most formally identified structure - a separate department with its own coordinator and personnel, training and reporting forms. This structure can be called "Division of Labor." Charged with the responsibility for spiritual care which includes "long-term counseling" and bereavement services, this department has contact with all patients and families rather than providing service upon referral. Although any staff person or volunteer may provide spiritual care, the Spiritual Department conducts all spiritual assessments, presents spiritual goals for care plans and is primarily responsible for the provision of this service.

Table 4.2

Typology of Spiritual Care Program Structures

	Formal Identification within Agency		
	Low	**Medium**	**High**
Division of Labor	HP	—	—
		—	HJ—
	—	—	HRC

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In contrast, HP presents the least formally structured program. There is no department, and no single person is held responsible for the service, although the medical center's Chaplain attends all team meetings and renders spiritual care upon request. This structure exemplifies an "Integration of Labor" within the agency. All staff and volunteers are considered "spiritual care providers." Responsibilities for assessing spiritual needs, identifying spiritual goals for care plans and providing the care, including bereavement services, are all integrated within the interdisciplinary team. Support, consultation and education are provided by the Chaplain and the administration.

The spiritual care program in HJ is less formally structured than in HRC but more structured than in HP. It is also more integrated than HRC but is more separate than HP. This structure is best identified as "Coordination of Labor." A clergy heads a separate department and is responsible for coordinating religious, spiritual activities with agency personnel and with clergy in the community. Since all staff and volunteers are considered "spiritual care providers," the Coordinator has no staff or specifically trained volunteers. Responsibility for spiritual assessment and bereavement services is housed within the Social Work Department. Planning for and providing spiritual care is integrated within the interdisciplinary team.

Conclusions

Each agency's particular history, values and type of authority, combined with the structure of its spiritual care program yields a description of the distinctive characteristics of its

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spiritual care culture. The charismatic leaders of HRC, responding to God's call, played a profound culture-shaping role in the history and formation of its values. The agency's "saga," based on religious theology and symbolism, defines mission as the reason for existence. Religion, and by extension spiritual care, is not latent but rather, "the roots of everything." The "division of labor" is evidence of this agency's specialization in this type of care. Despite elements of a professional organization, the "family" remains committed to their spiritual duty. To summarize, HRC embodies a familial orientation among its members and a missionary orientation to spiritual care.

Founded by health care professionals within a medical center and by a diverse group of community leaders including clergy, HP was established as and remains a professional organization utilizing legal authority. The integration of spiritual care with no assignment of responsibility is functional in this agency where "religion" remains latent as a result of its members' professionalism and the diverse religious, spiritual backgrounds of its clients. The structure affirms this diversity and the individual person's professional competence to provide appropriate spiritual care. In summary, HP embodies a professional orientation among its members and an individualistic, ecumenical orientation to spiritual care.

HJ shares characteristics of HRC and HP in its formation and current operation. It evolved from a medical center and diverse auspices and significant publics like HP. Yet, like HRC, it was especially attuned to a particular religious/ethnic group. HJ espouses

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values of professionalism and operates under legal authority like HP. However, it has a separate spiritual department like HRC. What makes the spiritual care culture of this agency distinctive? HJ embodies a unique combination of the professional and the traditional. It strongly espouses the values of professionalism, and is highly professionalized. At the same time, members are socialized in the Jewish culture and communal service system. Furthermore, they are expected to be knowledgeable of other religions and "religiously inclusive" in their orientation to spiritual care. This dictum to be culturally and religiously knowledgeable and inclusive results in a professional treatment of religion which is not latent. All members are responsible for spiritual care but this is coordinated by the clergy professional and not left totally to the individual service provider. In summary, HJ embodies a professional/traditional orientation among its members and a corporate, religiously inclusive orientation to spiritual care.

The varying attitudes of workers toward their spiritual care programs can be better understood within the framework of their individual cultures. Attitudes in HRC were uniformly positive, given the delineation of responsibility and the specific training of spiritual staff and volunteers. This agency's administrators expressed the absolute certainty in "doing it the right way" as long as they are faithful to their spiritual duty. A majority of people in HP expressed positive attitudes, pointing to the respect for diversity and informal support among one another. However, several expressed discomfort with the lack of training and the individual nature of their program. Administrators were comfortable with the current structure but expressed the need to "seek some common

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ground within the diversity," the primary goal of ecumenism. Most workers in HJ were positive and generally felt more confident than workers in HP, given the agency's commitment to education. However, several criticized the clergy for a lack of professional leadership. The administrators expressed comfort with the program's structure but the executive director envisions a reconceptualization of this component of care.

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Chapter 5: Meanings of Spiritual Care

Introduction

An exploration of the spiritual care process involves contextual dimensions such as the meaning of terms, person's religious, spiritual issues concerning dying and death and the organization which provides the service. Lofland and Lofland (1984) call these dimensions "units of social settings" for the purpose of analysis. As indicated earlier, the two primary units of analysis investigated in this study are the **meanings** and **practices** of spiritual care.

This chapter is concerned with meanings, and it opens with definitions of the terms "religion" and "spirituality." Other contextual meanings underlying hospice work in general and spiritual care in particular are identified and explored. These include: staff and volunteer motivations for engaging in hospice work; sources of stress experienced on the job; and coping resources employed by care providers. The chapter concludes with a cross-agency analysis of these dimensions.

Definition of Terms

Religion

Respondents described beliefs and practices, functions and some negative connotations associated with religion.

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Religious Beliefs and Practices

"Religion refers to faith, beliefs and practices that nurture a relationship with a superior being...a system of organized beliefs and worship which the person practices" (Emblen, 1992, p.43 & 45). Respondents' descriptions of religion reflected this definition which emerged from a content analysis of 30 years of nursing literature on definitions of these terms. Descriptions of beliefs included values, rules and commandments. Practices were defined as the outward expression of these beliefs, involving rituals, traditions and sacraments. Two clergy in Hospice Roman Catholic (HRC) explained:

> Religion comes from 2 Latin words which mean 'to live by.' My be-lief; what do I live by? That gets back to your values. Religion...is a way of **expressing** beliefs through the proper rituals... provided by a community of people who share strong spiritual values.

> Religion is those things that we were taught about God through Sunday School, parochial education, or catechism. There are certain rules and commandments that we're to live by, and rituals with sacraments are part of that.

Functions of Religion

Religion performs functions. It provides a sense of ultimate meaning and a set of core values for life. It also helps people discern meaning from pain, in order to make suffering sufferable (Roberts, 1990). Religious beliefs and practices help terminally ill people cope with their dying and death. A volunteer who was also a seminary student in Hospice Jewish (HJ) said:

> I believe that having such a deep well to draw upon can be of great advantage in one's spiritual quest. You are able to sit on the shoulders of giants when you're trying to answer some great questions of the universe.

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Negative Connotations

A few identified negative connotations ascribed to religion: "dogma," "judgement," "divisive," "exclusionary." A nurse, a social worker and a volunteer in Hospice Protestant (HP) explained:

> I see religious as divisive...Religion has connotations of denominations.
>
> Hellfire and brimstone...especially among conservative Christians.
>
> Religious practice and being religious...have a more negative connotation; people do it because they're supposed to...

Spirituality

Spirituality is an internal, intangible, transcendent process or journey which provides one's meaning in life, translates into caring actions and relationships with others and integrates other dimensions of human life. These qualities identified by the respondents are consistent with definitions in the social work, hospice and pastoral care literature (Morgan, 1988; Mauritzen, 1988; Ley & Corless, 1988; Canda, 1990; Corr, 1992; Emblen, 1992; Berggren-Thomas & Griggs, 1995; Derezotes & Evans, 1995; Dudley, Smith & Millison, 1995; Derrickson, 1996).

Internal Process

This internal, human dimension is one's "essence," or "core" which **moves** the person. Two clergy and a volunteer in HRC shared these descriptions:

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> Spiritual is core, life, heart of the matter. The thing that motivates us and moves us...The thing that really matters and is vital to emotional and physical whole being.
>
> ...whatever that essence in me that makes me get up in the morning to do what I have to do...The forces in me to make me who I am. My essence. My get-up-and-go...When good things are happening, my spirit is high and with bad things, my spirit is down.
>
> Spirituality kind of draws you from the inside, which for every one of us is **different**...Something that I see coming from inside...For patients, it's something in their eyes, a gentleness.

A nurse in HP called spirituality "A person's essential goodness. Spirituality lives in energy not dissipated." According to a nurse and a physician in HP and a volunteer in HJ, this internal process is "non-material" and, for some, "undefineable."

> Spirituality to me is attention to the non-material. Anything that goes beyond the concrete....Spirit creates matter. Matter is just a form of spirit.
>
> ...it has to do with things out of our control and things we don't understand...We don't understand life or death and why.
>
> I think spirituality is the attempt to find your place in the universe. Spirituality is that aspect of life that cannot be explained. It's ineffable.

Most respondents believe that a spiritual dimension exists in every person although it is difficult to discern at times. A nurse and a volunteer in HJ explained:

> Spirituality is in everyone, in nature. We're not just bundles of chemicals. We need to know answers or know that there are not answers to everything - there is some unknown.
>
> It's not something you have or don't have. It's just the building block of everything you know...To me, everybody is a spiritual being but some people are not aware of that.

A volunteer in HP shared her experience with one patient:

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> I had a patient who committed suicide - very hard. Where was God's spirit in him? I feel spirit as a sensed presence. Even with a person who doesn't seem very likeable, I say, 'I trust you're here' to God as a prayer.

Source of Meaning

The spiritual journey provides the source of meaning in life and in death. A nurse in HP struggled to put this into words:

> My spirituality might be the idea of life going on and what we get from life and how we deal with life as it is and the world itself. When we die, we die; but we do in some way regenerate...Life and death is a process. When we die, the body returns to the soil from which come flowers.

A clergy in HRC explained that a person's spirituality comes into play for the patient when:

> ...they connect with the family, loved ones that have passed away. They feel that they're going to be reunited with them...There's a hope that some people do have, whether religious or not, that hopefully when they die, they'll be reunited with those who have passed away. That they would feel at one with nature, God, with themselves, the world.

Expressions of Spirituality

A clergy in HRC described the unique quality of a person's spiritual dimension:

> The moral and ethical is spiritual...When he was in a concentration camp in World War II, Victor Frankl said, 'You can take everything from me, but you cannot take my decision on how I'm going to respond to what you're doing to me.' And that clearly enunciates the spiritual dimension of a person's life, because there were people in the concentration camp who actually went around and distributed their meager amounts of food to those who were less strong. There were others that went around and took the little that others had and kept it for themselves. What differentiated them from one another? It was their spiritual decision to **give** or to take.

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The spiritual dimension is expressed in a person's actions and relationships with others.

Staff and volunteers in all three agencies discussed this:

> Spiritual is not just a belief system but an actual practice day to day; something that affects your life day to day. Being in touch with the higher power within yourself.
>
> I think spirituality is what makes us people. And it isn't just one thing like independence; it's a lot of things. It's our empathy, our compassion for each other, perhaps our own self-confidence – how we feel about ourselves and our own image.
>
> Some sort of ability to relate to something other than yourself and beyond a human, behavioral level (e.g., husband/wife relationship)...The sensitivity to an existence other than here and now or an existence other than behavioral is the spiritual relationship.
>
> Spirituality is the constant desire to pursue your relationship with whatever being...(You) can have communion with nature, or other spiritual relationships.

The spiritual care provider actively uses her spirituality in her work relationships.

Spirituality actually defines the quality of the patient relationship according to a volunteer in HP:

> ...it (hospice work) is a relationship with these people; an **honest** relationship...People refer to it as love. But it is acceptance and respect more than anything else...It's respect for the other person's right to be just as foolish as I am on occasion; just as selfish, generous, giving and pompous.

For a nurse and a clergy in HP, spirituality facilitates acceptance of the patient.

> ...to recognize that even if you don't like behaviors of that person or how they are, that in the eyes of the Lord you are both children of the Lord and very much equal and that your relationship to one another is important to Him.
>
> Spirituality, if it has any integrity, is a big field. It's because it can allow both the strengths and the weaknesses of all positions **to be**...I can put up with someone's rough edges a lot easier now.

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Spirituality is a gift to be given to others, according to an administrator in HRC.

> When I think about spiritual, I think about taking the gifts that we have been blessed with and applying them, whether it's making life better for someone or to make life easier or solve someone's problem...When I look at the staff and the gifts and talents they have, these are recognized always as God-given...This is what they bring to whatever situation that they try to make better...It's what heals...and comforts.

Transcendent and Integrating Dimension

The spiritual dimension transcends and makes possible the integration of other dimensions of life. A nurse in HJ described the "greater essence" of this dimension:

> ...people have a physical body, a psychological self and a spirit. This is not a Baptist spirit... or a Jewish spirit, but an essence that is greater than the sum of all their parts, and an essence that doesn't die with them when their physical bodies die but goes on.

A clergy in HRC described its integrating power:

> Spirituality is the ability to integrate all the dimensions of my life into one driving force that moves me to achieve the best of what I can possibly be...Whatever is driving you this moment or is giving you direction is the result of your being able to integrate all of your life experiences, finding meaning in them and then translating them into that which gets you up out of bed every morning and moves you.

This clergy explained this integration in the life of Harold Kushner, a rabbi, after the death of his son.

> The death of his son was the most profound spiritual experience he ever had. He had to go back and reexamine everything he believed in...Then he was able to integrate that experience of his own pain with his ability to become a much more empathetic and compassionate human being...When you say the word holy, people get scared...But holy means wholeness. The ability to integrate all of my psyche, my emotional strengths and weaknesses, my life experiences, the things that have shaped my values, the things that have validated for me what I believe as a human being...

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Religion in Relation to Spirituality

The social work, hospice and pastoral care literature all draw distinctions between religion and spirituality and indicate spirituality as the broader concept (Spencer, 1961: Canda, 1988b; O'Connor, 1982; Amenta, 1988; Mount, 1993). According to the respondents, religion and spirituality each have distinctive qualities. They may also be experienced in union.

Comparative Qualities of Religion and Spirituality

Religion is tangible, human-made and institutional compared to spirituality. Two nurses in HP and a volunteer in HJ described these qualities.

> Some people cling to their religion and use that as their spirituality...Their spirituality stems from something that they think of as a tangible being...or tangible thing. What they get from going to church, Christ, heaven and hell...
>
> Religion is the framework that houses spirituality according to what one particular person can understand and believe in (rules, rituals).
>
> Religion is the attempt to institutionalize spirituality...an accumulation of spiritual experiences which are made part of one's union and consciousness.

A clergy in HJ and a nurse in HP explained that spirituality is more "universal" and "private" or "individualized" than religion.

> Spiritual is more all-embracing, and it's... something that each of us can touch in some way, maybe through music, drama, or poetry.
>
> I think spirituality is very self-defined, individualized...I see it as a oneness with the world, nature, other...I guess also a part of self identity.

A social worker and a clergy in HJ and a nurse in HP described how people can be religious and not spiritual and vice versa.

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> The two are not mutually exclusive but can be... I have found that someone can be religiously observant but seem to express very little sense of spirituality.
>
> I recognize that there are people who will not be a part of any religious tradition whatsoever but say that they believe in God: 'I was born Jewish but don't practice it. But I feel God is with me; I feel Jewish in my heart.'
>
> Someone can be extremely spiritual and not follow any religious tradition. If they have an awareness of their own worth, glory; if there's something greater than themselves; if they only believe in themselves, that can be a very spiritual belief.

The above descriptions make distinctions between something which is externally communicated, practiced and/or imposed versus something that emanates from within the person. Religion is the former and spirituality the latter.

Religion and Spirituality Combined

Several described how religion and spirituality can be combined. A social worker and clergy from HJ explained:

> There is a tension and non-mutual exclusivity between religion and spirituality...The key is to try to find the proper balance (between the two) in one's tradition.
>
> The truly religious person trys to have both. The word religion in Latin means 'to bind together.' It means you're binding yourself together with other human beings...Even mystics among Jews are always together. In the Jewish tradition you get to God with others.

A clergy in HRC explained how a person's life is enriched when his spirituality is combined with religious involvement.

> When you have somebody who has a strong connection religiously with an organization like a church, no matter what their religious affiliation is, and they get support from that, that's the best of all worlds; it really is.

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Motivations for Hospice Work

Working intimately with terminally ill people in physical, psychic and spiritual pain and enduring repeated losses of relationships through death can be emotionally and spiritually exhausting. What attracts people to this demanding occupation? The writer found that hospice workers are motivated for personal and/or professional reasons. Many find the integration of work with personal experiences and beliefs to be especially fulfilling and sustaining. Finally, some view their work in hospice as a reflection of their "religious journey" or as a "vocation" or "calling."

Personal Motivations

When asked why they chose to work with dying people in hospice, many providers described a personal experience with death. Volunteers in each agency related their stories:

> A good friend died of cancer. I did a lot to help...But I knew there was something more that she needed and...after she died I heard from her husband how much visits from another friend had meant to her... they would just sit and be together...That gave me the idea that I'd like to be able to do that for somebody someday.
>
> I got involved in grief work as a result of losing my daughter who died the day she was born. I knew first hand pain...Once I had resolved it, I thought, 'I can make sense of my experience and make sense of her life if I live my life...taking the pain and helping others with their pain'...Came to a real spiritual awareness and through that to hospice.
>
> Kenneth, who had Lou Gehrig's disease, had no place to live so I invited him to stay with me...Was with me up until 6 months before he died...It was very fulfilling and meaningful to be able to assist in his process.

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An administrator who had been a clergy said,

> The core of my old church was the single elderly female population. I was very involved in their medical care...I ended up moving one woman into my house where she died.

Volunteers in each agency had experienced the services of hospice during the illness of a relative.

> My father got cancer, and lived with us until he died. There's no question; I would have never been able to do that had I not been involved with hospice. The whole thing just worked out very well; it was a very special time.

> My son died of AIDS. I was his primary caregiver. I became enthused with hospice and after his death asked how I could help.

> My wife was a patient here. I made up my mind to give back a little of what I got here...The staff cared for **me, too** (tears)...It's like my extended family now.

Many in HRC were drawn by a prior relationship with persons in that program. A nurse explained:

> I worked in a hospital with (agency's directors). (Agency director) was present at the birth of my first child...I can't imagine going anywhere else. I've brought all of my children here. One daughter works and one volunteers here.

Professional Motivations

Hospice demonstrates a particular philosophy of health care which emphasizes palliative, whole person care, including the spiritual dimension, and patient control of care (National Hospice Organization, 1992). This philosophy, which represents a radical departure from the care received by dying people in hospitals, attracted many staff, particularly nurses. Goodman's study (1990) of health care professionals trying to serve terminally ill patients

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in a hospital indicates reasons why the hospice philosophy is so attractive. In a hospital, there is a basic lack of congruity between the organizational structure and philosophy of care, and the needs of dying patients. In this setting oriented towards cure or at least improved functioning, a dying patient represents "failure." Caring for a dying person in this setting presents the professional with a profound disparity between the socially valued goals of professional health care and a lack of institutional and practical means to achieve the goals. A person in this situation will, according to Merton (1968) experience anomie or normlessness, which can be existentially distressing. Goodman found that nurses, compared to physicians and social workers, had the most contact with very sick patients and they had the least control over allocation of their time. Hospice presents a structure and philosophy of care which is congruent with the needs of dying people. The nurse (and other professionals) can fulfill the socially valued goals of professional health care with the support of the health care insititution. Furthermore, compared to the hospital setting, the nurse in hospice becomes more dominant in providing medical care while the physician's role is more consultative. Three nurses in HP and HJ shared their experiences moving from a hospital to hospice.

> In nursing school I came across some very unfortunate situations where people were not being allowed to die with dignity...It reinforced how important it was for people at least to have an opportunity to make the choice.

> Hospice is more wholistic, more choices... Spirituality is why I'm in hospice. The patient is more than a diagnosis, a body part - **all** parts need care...In hospice, you are able to get close to wholistic care.

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> I chose hospice. You can really make a difference in living and dying. The quality of life. You can be very instrumental in keeping the family unit on track.

A physican in HP related:

> In medical school I became interested in patients being able to die peacefully. During residency I did a rotation at a hospice. I learned how to be comfortable with persons dying and helping the family to be comfortable.

For several clergy, hospice work is an expression of a long term interest in death and dying. A minister in HRC with a background in social work and nursing said,

> In the church many times, ministers have problems when they visit (dying) people; some shy away from it, have difficulty with what to say.

A clergy in HJ shared:

> I've always been interested in death and dying... Dealing with death and dying really brings out all the issues of spirituality and religion that I am interested in.

Integration of Personal and Professional Motivations

Danzig (1986) said the social worker's task is to strive toward an integration of one's personal and professional values. The opportunity to realize this integration provides a powerful motive for many. Following a career change from business, a nurse in HP described her work as "...being able to integrate what you believe about living and dying...to live it out." For a social worker in HJ, hospice was the answer to his search for work in a health care setting where his spirituality would be welcome.

> I had always agreed with the hospice philosphy of care...Also, I have a strong religious background; spiritual care is the most important part of hospice work.

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Following her move from an oncology unit in a hospital to hospice, a social worker in HP shared:

> It fit better for me...It allowed me to provide some alternative things that I couldn't in a hospital setting like therapeutic touch. Allowed me to feel more comfortable with my own philosphy of life and death...

A nurse in HP who had worked in a family practice office found hospice very appealing because:

> ...it is very family and life cycle-oriented...I grew up with it. I was raised with caregiving within the family. My grandmother raised me, and now she lives with my family.

Following the death of her father, a social worker in HJ:

> ...found grieving to be unexpectedly painful but also unexpectedly wonderful. I found the whole illness/death/dying/grief field to be very fascinating. I went back to social work school and got placement at the hospice.

This integration of work and personal philosophy is particularly meaningful to some who have experienced major trauma in their lives. A nurse in HJ shared her story.

> I'm a non-Jewish Holocaust survivor. My paternal and maternal families were killed. It's all about losses for me. Father died suddenly; mother had Alzheimers; I lost a child and my husband. I have survived because other people have helped me survive. I wanted to help others survive...started doing hospice...This was something that I could give someone - comfort, nurturing and spiritual support.

Religious Journeying

Hittle (1994) describes her childhood experiences with death, her rage at God, her decision to enter nursing and a:

> ...deepening sense of my own spirituality...I continue to grow with every death. Perhaps that is what my journey in this life is all about (p.24).

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Like Hittle, several respondents connected their present work with their evolving religious, spiritual beliefs or their "journey." A physician in HP shared:

> Coming from a scientific background, this was first time I was really questioning, 'Why?' The patient's mother got me to start believing that there was more to it than what we see...something more than what's on the surface.

A clergy in HP with over 30 years of pastoral care experience described his move from western to non-western religions.

> The issue of spirituality for the first 20 years was limited to the western religious tradition...In last 20 years, universalism, cross culturalism and wonderful dimensions of...worldwide spirituality have evolved.

A former Roman Catholic nun in HP shared her spiritual "journey":

> I experienced losses; developed survival/coping skills. Out of suffering comes growth and greater depth...The spirituality evolved into a core peace... peace from chaos...

Several described struggles with their "childhood religion." A nurse in HP and social workers in HJ described their journeys.

> At 17 years old, I told God off...Through the help of a Sister, I have been able to grow through a lot of the anger...I am less angry now...I am learning about forgiveness, letting go, use of support systems.

> I was brought up Jewish. I did all the ritual stuff, but never felt spiritual. I don't want to know about prayer books and those old guys. I want to know about today; what can help me today. Then I got the spiritual stuff.

> In my late 20's I moved away from Christianity... Being here (hospice) maybe brought me back...I tried Eastern religion; use parts of its philosphy, but Christianity works for me culturally...My own religion is a combination of Western and Eastern...The main message is to acknowledge the spiritual dimension.

Examples can be found in the social work and nursing literature of professionals viewing their occupation as a vocation or ministry. According to Lane (1987),

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> ...this response flows from a deep relationship with a transcendent God, or in a more secular vein, from a deep indentification with a suffering humanity... Nursing has a deep personal meaning in terms of religious or humanitarian values. The nurse makes the connection between what he or she is doing and the ultimate meaning and purpose of life (p.336-337).

The "Code of Ethics" of the North American Association of Christian Social Workers (NACSW) emphasizes the profession as a special calling. "The values of social work are Judaeo-Christian in origin" (Johnson, 1978, p.44). The helping process has its Biblical basis in God's commandments and the life of Jesus Christ (Johnson, 1977; Watkins, 1979). This foundation infuses social work with a "divine purpose." Chiwezer (1994), Levine (1990) and Bubis (1980) indicate intimate relationships between Jewish concepts of redemption, tzedakah and chesed and the Torah, giving a "transcendent quality to our work" (Bubis, p.233). A few respondents cited their religious or spiritual belief system as the primary motivation for hospice work and think of their occupation as a "ministry." A volunteer and an administrator in HP explained:

> I am a born-again Christian...Not the stereotype - the fundamentalist who shoves it down your throat. Born-again to me is what's in the Scripture; born again of the Spirit...Accepting that Christ has come to redeem your sins and cleanse you, that you have given your life back to Christ as a cleansed and forgiven sinner.
>
> I consider myself a religious person because this is my religion. I consider my work my worship. It's my profession and vocation. This is more or less my witness.

A nurse in HJ put it simply: "Coming to hospice for me is the end of my journey. It is my epiphany...I was meant to be here."

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Sources of Stress

The social work, hospice and nursing literature describe and study sources of stress experienced by professionals working with terminally ill people (Koocher, 1979; Davidson, 1984; Yancik, 1984a&b; Davidson, 1985; Gray-Toft & Anderson, 1986-87; Vachon, 1987). For this study, the writer referred to the definition of stress offered by Lazarus & Folkman (1984). A person experiences an event or situation as stressful when she appraises it as taxing or exceeding her resources and endangering her well-being. Staff and volunteers were asked to identify the major sources of stress in their work. Their responses were consistent with social workers and nurses interviewed in hospitals and in hospice who identified two sources of stress: issues directly involving the patient and family; and issues related to other parts of the job.

Office-Related Stress

"Environmental" or "work-related" sources of stress such as staffing patterns, lack of staff support and interdisciplinary staff conflict at times cause greater stress than "emotional concern for patients and families" and "communication with patients and families" (Yancik, 1984; Gray-Toft, 1986-87; Vachon, 1987; Masterson-Allen, et. al., 1987). Over half of the workers in this study identified the "workload," "the bureaucracy" and "office politics" as major sources of stress. A nurse on the in-patient unit in HJ feels "...unable to respond to evident patient need due to (the) overload of responsibilities."

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Referring to communication with other staff and completion of necessary records, a nurse in HJ talked about:

> ...all the bureaucracy. It's not really the job itself, it's all the surrounding things that are part of the atmosphere...I feel stultified in the office.

A social worker in HRC referred to "...stress resulting from organizational growth and being a manager."

Patient and Family-Related Stress

A comparatively small number described the inability to meet a person's needs or "feeling useless" as very stressful. A volunteer in HRC explained that her work is most stressful:

> ...when people linger a long time, and they're ready. They've looked back...they've put things in order, they're pleased with the relationships they have now...and they **don't die**. They're watching their bodies fail them...You've already said all the things that can be said and so you're just waiting.

A few shared experiences with "tough patients" and families. A volunteer in HJ talked about "...hostile patients and families that are irrational." A social worker in HJ described: "Taking abuse, grief from difficult patients...people that treat me or family members poorly."

Spiritual Issues

It is noteworthy that very few care providers identified spiritual issues as stressful. Those who did referred to their struggles with "unresolved deaths" and the "why questions." An administrator in HP and a music therapist in HJ described these situations.

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> Can't control pain, symptoms, vomiting...It's also difficult when things don't work out the way you wish they had. That can be personal and not what the patient or family wished.
>
> The relationship with the family ends...In some ways this job has made me get angrier at God when I see people suffering. I find myself in a spiritual/moral dilemma. 'Why? How can this be happening?'

Coping Resources

Lazarus and Folkman (1984) define coping as constantly changing efforts to manage external and internal demands appraised as taxing or exceeding a person's resources. Coping is not equated with mastery over the environment and can include efforts such as tolerating, minimizing, accepting or ignoring in order to maintain self-esteem and hope in the midst of irredeemable situations. This defintion is particularly meaningful for people working with the terminally ill and for the dying person herself.

As stated earlier, a relatively small number of respondents experience stress related to their emotionally and spiritually demanding work with patients and families. An investigation of coping resources clarified reasons for this finding. A strong connection between work and one's religious, spiritual beliefs emerged as the primary coping resource. Other resources are agency support systems, relationships with others and particular activities.

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Connections Between Work and Religious, Spiritual Beliefs

All but a few of the respondents (96%) connected their current work with their religious, spiritual beliefs. Work has profoundly influenced beliefs and lifestyles; and religious, spiritual beliefs have sustained workers, making them more effective spiritual care providers.

Impact of Work on Beliefs and Actions

Yancik (1984) and Davidson (1984) identified a sense of satisfaction and mastery as a primary coping resource. This sense of satisfaction is deepened, according to workers in this study, through their religious, spiritual belief systems. For many, the work has changed or strengthened their beliefs in "the Spirit" or "God," and their beliefs related to death. A social worker in HJ and a nurse and administrator in HP explained:

> Since I've come to hospice, I've gotten a sense that there is something bigger than we are. There is some kind of spiritual energy out there. I think it happens to many hospice workers. They're spiritualized during their work.
>
> It's opened up my beliefs. I begin to marvel at all the ways God reveals Himself. I always had black and white thinking; God couldn't be in pain, only joy. Yet I see Him there now...
>
> ...My beliefs about God and afterlife have been reinforced...I've always believed in the strength of the human spirit but I've **seen** that. I've seen people in very terrible circumstances able to move beyond that.

The work has also influenced people's lifestyles and practices as related by a nurse in HP and a social worker and nurse in HJ.

> I just started going back to church because of the patient with incredible spiritual strength. I realized I had gotten out of the habit of going. It was time to go back.

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> It reinforced my feeling that what's most important in this life is our relationships with other people and taking care of each other.

> Beliefs are more meaningful; work has clarified a lot of them...Life is sweeter because of hospice...Religious things are more important to me in my spiritual life; traditional things have a sweeter taste to them.

Taylor and Amenta (1994) found that work with dying patients provides a primary source of "spiritual support." Workers in all three agencies find inspiring the opportunity to meet, to serve and to be served by the patients and families. Two nurses in HRC and HJ related:

> I visited a patient in a nursing home. She was surrounded by machines and tubes. I leaned down beside her to literally crawl through the tubes to get to her, and I asked her, 'So how's life'? And she said, '**Life is good**.'

> You see people grow so much as they die. Patients reconcile with family members, people and families express gratitude for each other...family and friends take extraordinary care of each other. This caring for each other has to come from something beyond human beings themselves.

A social worker in HJ learns from her patients.

> I'm from an orthodox Jewish background. It was rote which didn't satisfy the intellectual part of me. Being with them (Black Baptists) has been an incredible experience for me.

A volunteer in HRC finds hope:

> There is so much **hope** in all the people you visit...They live until they die...They are trying to avoid any pain, suffering, or anything going wrong with their family, but they are really living until they die...There's such strength there, it's really hope and trust in something...

Telling the story of a 35 year old friend who died, a nurse in HJ shared:

> She was Lutheran. A simple faith. Her life was right with God; this brought peace...This was a grounding experience for me. I saw faith work.

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Many experience deep fulfillment in the "privilege of serving" people at a time "when others shy away," making a "real difference in perons' lives - and deaths." A nurse in HP and a volunteer in HRC described this experience.

> Being with (patients) in their time of need. It's an honor to be invited in - the equivalent of seeing a baby born.
>
> It's made me take another look at Holocaust survivors and how they struggled to stay **alive**! Everything was against them, they could have so easily let go...and that's what you see in people - it's very hopeful. I'm different because of every life I've come in contact with...You've seen them at such a time in their life, and they share with you - what a privilege to have people share part of their life with you at that time.

In view of her initial expectations, a music therapist in HJ found her work to be surprisingly satisfying.

> The work is so fulfilling! It totally changed my life. It feeds my soul...As soon as I'm bringing pleasure (through music) I see the face change or the breathing relax...I know that's God doing it through me...I'm a good person for doing this job.

A volunteer in HRC described the fulfillment experienced when present at a "good death."

> The person dies **knowing** that other people will remember him with love and the family said good-bye to this person and will be so thankful that they had this time...When you see a person who can come around to an acceptance...when things come together and you can see a peace come to a person, who, when you first met them, wasn't peaceful at all...That's the most gratifying. If you can witness that, that's wonderful.

A nurse in HP described the dying process of a young mother with a small child:

> An unbelievably unique experience...similar to being a midwife. Lot of hands-on care/massage; talk about love of and for patient with family and child present and involved. A very warm experience for death!

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Impact of Beliefs on Work

Taylor and Amenta's study (1994) develops the "intuitive assumption that an individual's spirituality and religion will inherently influence attitudes and beliefs regarding spiritual care" (p.33). Hospice professionals who describe themselves as more spiritual experience greater satisfaction in their work (Millison & Dudley, 1990). A nurse with a sense of calling to nursing is able to "...elucidate more clearly the struggles heard from the spirit of the patient" (Lane, 1987, p.337). Respondents in this study described how their religious, spiritual belief systems not only facilitate more effective spiritual care; for many, they are also the critical source of support for doing hospice work. Nurses in each agency and a volunteer in HRC explained:

> You can't do this work without relying on your own belief system...The Holy Spirit - I wouldn't go to work without it.
>
> I believe in a God who loves me very deeply, who loves each one of us more than we can imagine, who doesn't want to see anyone suffer, who wants to see us happy.
>
> I've always believed the reason for the interchange between human beings on earth is that they're here to help and support one another; love one another...It's (hospice) a natural extension and a way to put into practice what I believe...
>
> I believe that death is just a change, part of natural cycle...It's not so frightening. It can be peaceful. Patients have sensed that peacefulness in me.

Confronted with the need to reconcile the existence of suffering and death, care providers are sustained by their beliefs regarding evil and injustice. A nurse in HP and a clergy in HRC expressed their beliefs.

> God never promised us that everything was going to be easy. And for as much as there is a God at work in our lives, there are also torments and

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> temptations at work in our lives... This good life here on earth is really just a very small portion of our existence in the Lord's presence.
>
> I've never blamed God for evil and never seen evil as evidence of a limitation of God. I see evil as natural evil (earthquake) and objective evil (evil that people do to each other). I believe that my job is to release more God into the world. When that occurs, there will be less objective evil.

In HP, a 72 year old volunteer of 15 years who has "ministered" to over 50 dying people said:

> I made my peace with that a long time ago...I just think, 'It rains on the just and the unjust alike.' God doesn't send the problems; they're already here. Some things we're not going to understand.

The importance of religious, spiritual beliefs was made particularly graphic in response to the query: "How do you cope with the repeated loss of relationships of patients and families?" A social worker and two volunteers in the three agencies answered this question.

> ...I feel that people's departure is a blessing because they've gone on to something...People are suffering so...I'm happy for them. They're free from this.
>
> To me, she (the patient) will continue to exist. It's relationship and memories. I will have her to guide me for the rest of my life.
>
> I think the strength I have or maybe the grounding comes from my own faith and my own spiritual beliefs. A lot of it's difficult; you can't help but become attached to people, and of course, some people touch you more deeply than others; and when you lose them, no matter what their condition, it's a loss... unless you have some kind of a grounding somewhere and a faith, I think this would be difficult.

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Interaction Between Work and Beliefs

Rather than a one direction relationship between work and beliefs, a few respondents described a "dynamic interaction" or a dialectical relationship between the two. A social worker and a volunteer in HJ described this relationship in their lives.

> ...It's not that I bring my spiritual beliefs to work but that it's a very dynamic interaction between what patients and families say to me and how they respond and what my own beliefs are...
>
> I had a really strong faith coming to hospice. The intensity or strength of my faith has fluctuated some, but not in any big way...My personal experiences with God in my life reveal a God who chooses life...and is powerful - constantly faithful, abiding in steadfast love. And I've seen in these people... an incredible capacity to cope that has come from their relationship to God.

Other Coping Resources

The remaining coping resources include agency support systems; relationships with others and particular activities.

The Agency

Studies involving social workers and nurses in health care settings have indicated aspects of the organization which provide sources of coping. Davidson (1984) identified supervision, time-off and team/peer support. Taylor and Amenta (1994) found that other nurses and chaplains are supportive. Richman and Rosenfeld (1987) discussed the effectiveness of staff support groups that provide technical, social and emotional support. A good number of respondents in this study cited formal and informal agency support systems as important sources of coping. Informal relationships appear to be at least as

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helpful as formal support groups and memorial services. A nurse in HRC described the informal support among staff following a death in the residential hospice.

> We get together and talk about the difference that patient made, rather than holding it in and letting it build up. You have to share it with your co-workers. You have to let them know what you think they did that was so great or so effective with that patient.

A volunteer and a social worker in HP described their agency's support systems.

> Monthly meetings are important for a volunteer...We must be able to open up and share with other volunteers and hear problems...
>
> Staff support - we cry together in team meetings... Memorial services bring closure.

A social worker in HJ relies on formal and informal support.

> I use the support groups and know that they're really there for me...Team experience, working closely with the nurses. Very pleased that I have colleagues who have a good value base.

Relationships and Activities

Yancik (1984) and Davidson (1984) identified resources external to the worker's job such as relationships with others and particular activities. This study produced similar findings. A few noted the importance of family and friends. A nurse in HP related:

> If it's been particularly difficult, I have someone that is equally strong in his beliefs and faith and I have time to share and support.

Several named corporate functions and solitary activities which are helpful in coping with loss. A social worker and a rabbi in HJ and a volunteer in HP participate in corporate rituals.

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> Every once in a while it builds up and I go to a funeral...If I think it's important for a family member, I'll go to their funeral. A lot of time I go to funerals to mourn other people.
>
> I observe Jewish rituals, say the Kadish – special mourner's prayer – and remember them. That's a comfort.
>
> I contact the family right away as soon as I know about the death...Always go to the funeral or stay at the house during the funeral.

A social worker in HP and a nurse in HRC described their solitary coping activities.

> It is cumulative; the impact of a number of deaths builds up. You have to release it. (I go) still water canoeing; rent a sad movie and have a good cry.
>
> I take time for quiet for me. I always carry some books that I use to connect me with God. I find great solace in finding quiet meditation in the midst of all the business.

Cross-Agency Analysis

Definition of Terms

There was general agreement across the agencies in the definitions of "religion" and "spirituality" and their distinctive characteristics. Differences among the agencies can be found in who provided the definitions and in the language used. The rather uniform definitions in HRC were all offered by clergy or members of the spiritual department except for one non-spiritual staffperson, a social worker. In contrast, a variety of staff (social workers, nurses, clergy), volunteers and the administration all contributed to the definitions in HP and HJ. A proportionately higher number in HP offered definitions of spirituality than in HRC and HJ. Workers in HP also used more expansive, philosophical terminology while those in HRC more often referred to theologically based spirituality

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(i.e., "the Holy Spirit"). Respondents in HJ used both the theological and philosophical terms. Finally, a greater number in HP and HJ drew distinctions between religion and spirituality than in HRC.

Motivations

The vast majority of those who were attracted to hospice for personal reasons were volunteers in all three agencies. Approximately half of the staff, representing all professional disciplines and including the administration, were drawn for professional reasons in all of the agencies. An equally large number of workers in HJ joined the agency for both personal and professional reasons. More workers in HP and HJ than in HRC cited as a motive the ability to integrate work with their beliefs. A distinguishing characteristic of HRC is the vast majority of staff and volunteers who were drawn to the agency by its directors whom they knew personally or by reputation. Finally, a small number from each agency described their work as a "calling" or a "vocation." These individuals included a nurse and a volunteer as well as clergy. It is interesting to note the differences between HRC and the other two agencies in the evolution of people's religious, spiritual beliefs, or "religious journeying." Although a number in HRC discussed their religious growth, no one had changed her affiliation. This contrasts with respondents in HP and HJ. Over half of the workers in HP and one-third in HJ had changed their denominational Christian affiliation, had moved from Christianity to Judaism or vice versa, had incorporated Eastern with Western beliefs or no longer identified with any religion.

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Sources of Stress

Office-Related Stress

Although office-related stress was identified less frequently than stress related to patients and families, workers expressed much more anger and frustration with office work. While appearing to accept the stress related to patients and families as part of the job, they seem much less tolerant of "paperwork" and "the bureaucracy." One worker offered a possible explanation for this finding:

> I think it's a big fallacy that doing hospice work is stressful because it's about dying. It's the opposite. I think dying is what nurtures and feeds us. The stresses of every job are here but because we're caregivers, we're less tolerant of those stresses...Whenever those stresses interfere, we don't accept that as part of our jobs; like we shouldn't have to deal with that.

Lazarus and Folkman's (1994) discussion of positive and negative stress is instructional here. It is clear from the discussion on motivations that the workers are motivated by and find satisfaction in the opportunity to provide care. They experience stress related to caring for their patients and families as positive – an opportunity or a challenge to serve and to grow. Office-related jobs present negative stress – a mundane, meaningless nuisance - that impedes one's ability to do the "real work." Schneider's (1987) discussion of "the stressful paradoxes of hospice work" also helps to illuminate the hospice worker's experience (p.266). These care providers must manage a profound psychological and experiential gulf between the deep meaning and intimacy of work with dying people and the routine tasks of writing progress notes. The worker's quote above reveals the challenge in negotiating this gulf.

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Analysis of this source of stress across the agencies revealed that half of the workers in HRC and in HJ, but only one worker in HP indicated these stressors. This may be explained by the smaller size of this agency (half the number of staff in HRC and HJ) and by the comfortable work environment reported much more frequently in HP.

Patient and Family Related Stress

There were no major differences among agencies in the descriptions of patient and family-related stressors. Specifically spiritual issues were mentioned less frequently than frustration generated by one's perceived inability to meet people's needs in general. Fewer than five people across all three agencies identified "tough patients" as a stressor.

Coping Resources

The interview questions intentionally sought information to explore any relationship between work and one's religious, spiritual belief system. Three different types of relationships were reported among all disciplines of staff and among volunteers. Over half of the respondents in all three agencies described how their work has changed or strengthened their beliefs and practices. The remainder feel that their belief system has improved their ability to provide spiritual care, or they describe a dialectical relationship between the two, especially in HP and HJ. Whether it is described as unidirectional or dialectical, there is an interactive relationship between the worker's personal beliefs and her professional practice. The vast majority of respondents in all three agencies identified this relationship as their primary coping resource.

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The second most frequently named source of coping was the agency. Respondents in every hospice, but especially in HP and HJ, noted the importance of informal communication and support among colleagues and the agency's annual memorial service. Respondents in HJ also named their formal support groups as sources of coping. Workers particularly in HRC and HP noted the support provided by their administration and/or by spiritual care leaders. Finally, respondents in all three agencies identified similar corporate rituals or solitary activities as coping resources.

Conclusions

The differences among the agencies in who provided the definitions and in the language used can be understood as a product of characteristics of the agency and/or of the religious, spiritual backgrounds of the respondents. Agency characteristics refer to the culture, including religious/spiritual affiliations, and to the structure of the spiritual care programs. Given the relatively uniform Roman Catholic affiliation of the auspices, constituencies, clientele and personnel of HRC; and given its separate spiritual department with trained personnel, it is not surprising that the definitions were offered primarily by clergy and members of this department and that the language was more uniform and theological compared to terminology used in HP and HJ. The more diverse and philosophical language used in HP and HJ reflects the greater diversity and complexity of these agencies' auspices, constituencies, clientele and personnel as well as their spiritual care programs which are more decentralized than that of HRC. The

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phenomenon of "religious journeying," which was much more evident in HP and HJ than in HRC, is a further indication of the greater diversity within these two agencies.

Volunteers tend to be motivated for personal and staff for professional reasons in all three agencies. Beyond these similarities a different pattern of staff/volunteer recruitment emerged in each agency. The pattern is clearest in HRC where the vast majority of both staff and volunteers are drawn by its charismatic leaders. In HP staff are motivated primarily for professional reasons. In HJ, the number of staff motivated for personal and professional reasons equal the number attracted for professional reasons alone. These patterns reflect the different types of authority used and the values of each agency as well as the life experiences of its personnel. In HRC workers are drawn by the charismatic leaders to engage in the agency's mission. The pattern in HP reflects its professional culture and values. The pattern in HJ reflects the relatively greater variety in persons' life experiences including traumatic losses and the professional orientation of its everyday operations. This agency, which combines characteristics of both professional and traditional leadership and values appears to attract people who are comfortable with this dual orientation.

Given the clear differences in agency cultures, religious, spiritual affiliations and spiritual care programs, the similarity in reported stressors and coping resources is striking. Like previous studies of professionals working with the terminally ill. this investigation named sources of stress related to office tasks and to the care of patients and families. However.

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this study involving spiritual care providers revealed much less tolerance for the former than the latter and almost no stress related to specifically spiritual issues. Several providers explained this dynamic, pointing to the powerful, interactive relationship between their work and their religious, spiritual belief systems. This interaction is synergistic, creating an experience which transcends the worker's personal beliefs and her relationship to the dying person even in "moments of utter darkness."

This study presents professionals whose beliefs are nurtured and sustained by their work and/or who are aware of how their beliefs nurture and sustain them in their work. The description of this unidirectional and/or dialectical relationship contributes to understanding the complex relationship between professional practice and personal belief. and it addresses the longstanding concern among social workers about imposing one's beliefs on the client. Perhaps this is what Spencer (1957) meant when she encouraged the reintegration of religion within social work by "making affirmative use of one's religion" in practice (p.522).

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Chapter 6: Religious, Spiritual Needs and Resources of Patients and Families

Introduction

A necessary step in the rendering of any professional human service is an assessment of the client's strengths and needs in relation to the service. In order for it to be effective, the assessment instrument must accurately assess what it says it is assessing, and this requires a concensus regarding the meaning of key terms. In the assessment of strengths and needs regarding the provision of spiritual care, "religious" and "spiritual" are such terms. The previous chapter presented definitions of and differences between these terms. The following descriptions of religious, spiritual needs and resources of patients and families flow from these definitions and comprise an additional contextual dimension or unit of analysis in this exploratory study of spiritual care.

Respondents' descriptions of these needs and resources is followed by a discussion of: differences in needs and resources between patients and families; distinctions made between religious/spiritual and psychosocial needs and resources; the impact of these needs and resources on a patient's death; and the impact of these resources on survivors. The chapter closes with a cross-agency analysis of these issues.

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Religious, Spiritual Needs

Religious Needs

"Religion" refers to an organized system of beliefs and values that nurture a relationship with a supreme being; and are expressed through the practice of meaningful rituals and the use of symbols within a community or institution of people who share these beliefs and values. Respondents identified specifically religious needs associated with these **beliefs** and **practices**.

Religious Beliefs

Patients and family members express fears of dying and what happens after death according to their conceptualization of "God" and their religious backgrounds. A spiritual staff person in HRC explained:

> I think underlying a lot of problems is a religious-based problem in a belief system. The fear of death has a lot to do with what people are brought up with...and what is in that afterlife, if they believe in an afterlife.

A devout, Roman Catholic woman who was interviewed provides a meaningful example. This 84 year old woman immigrated to New York City from Italy when she was 10 and grew up in Little Italy in "a strong, Roman Catholic family and neighborhood." She married and raised six children. Family pictures and religious artifacts throughout her small home testified to the two most important things in her life. She talked excitedly about each of her children, giving details to the point that her eldest daughter and caregiver became embarrassed. When the topic of her religious faith was broached, her daughter said, "Her faith has been tested." Her brother died of dyptheria a year after

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arriving in America, one son died "at a young age," and she lost her husband two years after her son. Despite these losses and her own failing health, she answered questions about her beliefs in God, Jesus Christ and "Mother Mary" with absolute confidence. Asked if her beliefs help her cope with her illness, she said, "Yes! I pray every day!" However, this assurance abruptly deserted her when she was asked what she expected would happen to her after she died. She became silent and after several moments whispered, "I don't know." Her daughter quickly said, "You believe that everything is God's will, Mother; you believe in heaven!" The patient remained silent then left the room. She knew her husband and son were in heaven because of prayers, rosaries and masses said for them. However, believing in Hell and Purgatory as well as Heaven, she could not state with any certainty where she would go.

Respondents' opinions differed regarding the intensity of post-death anxiety experienced by Jews and Christians. A nurse and a social worker in HJ expressed this difference:

> These problems more with Christians than Jews - (Jews) seem more comfortable with death like nothing is hanging over their head.

> My Jewish patients are not wondering about whether they're going to make it into the afterlife, whether they're going to heaven. But they still wonder what comes afterwards. Maybe in Judaism that's more of a problem. The Christian patients...have a peace in knowing that their lives are in God's hands and they're going to heaven. With Judaism you don't necessarily know what's afterwards.

Patients struggle to understand the meaning of their illness and suffering within the context of their religious beliefs. A clergy in HJ presented the questions some people ask.

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> ...if God is love, how could this happen? If God is Creator, then why can't God have created some good things instead of bad things?

A spiritual staff person in HRC explained how this struggle sometimes involves a reassessment of one's relationship to God.

> Some people are taught that they have to praise and thank God all the time and don't feel they have permission to get angry at God or lament.

Religious Practices

Respondents frequently cited the need for ritual and receipt of the sacraments, particularly among Roman Catholic patients and families. A clergy and spiritual volunteer in HRC related:

> They want to be sure the priest gets out for annointing of the sick. Even fallen away Catholics need last rites performed. They need the ritual of the religion. They need confession.

> Catholic people who have not gone to church for many years want communion and last rites at the end just to be on the safe side. Depending on the situation, there might be problems in family and they feel that it's important from a religious standpoint to absolve them all...

Experiences with Religion

Several respondents identified as religious issues patients' alienation from or rejection of religion based on their past experiences with a religious institution. A clergy in HRC explained: "Most people who have rejected religion are people who have somehow been hurt by the church." A social worker in HP talked about a patient with AIDS who was told by a clergy that he was an "abomination to God." A nurse in HJ told about how the church had refused to give communion to a terminally ill man who had lived with a

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woman for many years outside of marriage. She explained, "The most important thing for him was to take communion at that time in his life." An administrator in HP told of a Japanese woman with tremendous pain management problems.

> She had converted to Christianity which was unheard of. Her husband was the epitome of Japanese culture. As the disease progressed, she spoke Japanese again. Minister's visit which was comforting later became irritating; scripture reading became unappealing...The things that would comfort a Christian were no longer comforting to her...I think she had tremendous guilt over converting, feeling she had betrayed her family and religion.

Feelings about one's religion which have been profoundly influenced by a traumatic life event can be reactivated by illness and the prospect of death. Survivors of the Nazi Holocaust present graphic examples of this dynamic. The literature documents the particular difficulties experienced by Holocaust survivors and their families when faced with aging, illness and infirmity (Danieli, 1981; Edelstein, 1982; Steinitz, 1982; Rosenbloom, 1983; Cohen, 1991; Zilberfein & Eskin, 1992; Safford, 1995). Developmental theory presents old age as a time to achieve "ego integrity" through reminiscence and life review (Erikson, 1982). Stafford (1995) states, "For the survivor it may be impossible to integrate the hell of the Holocaust" (p.139). The death of a spouse may reactivate the "unfinished business of mourning" (Rosenbloom in Cohen, 1991, p.227). Danieli (1981) states,

> The most painful and intolerable struggle underlying all attempts at coping with integrating the impact of the Holocaust...is the genuine impossiblity of mourning. As one 74 year old recently rewidowed and the sole survivor of a family of 72 put it, 'Even if it takes one year to mourn each loss, and even if I live to 107 (and mourn all members of my family), what do I do about the rest of the 6 million'? (p.197).

In fact, mourning at the time of the Holocaust would have been suicidal.

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> Tears and crying, wailing and loss of self-control were the most dangerous reactions in the concentration camp. Such outbursts would have been the reason for the cruel enemy to select the pathetic victim for the gas chamber (Merloo in Cohen, 1991, p.228).

Physical deterioration and illness have special meaning for survivors. As a result of the loss of bodily functions, survivors may reexperience the humiliation, degradation and feelings of helplessness suffered under the Nazis (Cohen, 1991). Furthermore, illness and vulnerability usually meant an automatic death sentence (Zilberfein & Eskin, 1992).

Spiritual care providers in this study found the pain and suffering in Holocaust survivors to be "the most poignant."

> 'But God, I suffered through the Holocaust. My whole family was wiped out. Why am I going through this now'?

Many of the workers in HJ noted the extreme orientations to religion among these patients. A nurse explained:

> The response to religion is either great depth of commitment or cynicism/anger...Same with family members - it permeates the family unit...Holocaust survivors have experienced a psychosocial trauma. Religion either got them through it or it was the cause.

Spiritual Needs

"Spiritual" refers to an internal, transcendent process or journey which provides meaning in life and loving, fulfilling relationships. The spiritual dimension includes the religious, but is not confined to it.

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Fear of the dying process and anxiety about what happens after death were the most often cited spiritual concerns among persons with no religious affiliation. These concerns were related to general fears of the unknown rather than to any religious belief. A social worker in HJ shared questions voiced by some patients.

> 'What happens after I die? Where do I go'? Some people have no beliefs - believe that death ends life; it's over. The unknown can be terrifying.

Post-death anxiety was often associated with a questioning of the meaning of one's past life, at times resulting in a sense of guilt and/or remorse. An administrator in HP and a social worker in HJ gave examples.

> Guilt is a major issue. Things that they've done in their past life that they feel bad about. Maybe it's not even justified...Also, that their life has had no meaning.

> 'Have I used my life well, done well by people I love? Am I leaving an appropriate legacy'? Feelings of incompletion or guilt about things they've done; remorse.

The need for caring relationships at the present time and remorseover past relationships were frequently noted. A clergy in HRC, a volunteer in HP and a nurse in HJ explained:

> When you get someone in distress, there's usually been a ruptured relationship in their life that they haven't been able to make their peace with. They feel guilt about things they never got, issues that they abandoned, people they've betrayed or abandoned and inability to resolve that.

> ...she needed someone to give her unqualified love. Someone to feel that her story was a very, very important one.

> Lot of unfinished business; lot of real concrete stuff holds people back...Lack of communication, unresolved feelings, anger, old resentments.

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Clergy in HJ and HRC reported patients' anger at and fear of abandonment by other people and God.

> Questions of anger directed towards everyone... 'Why is this happening to me or to anybody? What did I do to deserve this'?...Why take a young father away from a family of 3 children and a wife? With those thoughts comes the disbelief, the sense of abandonment by God or anger with God.
>
> I think for patients who have lived the good life, done the good things, been the good people and who conceptualize God as a person who inflicts pain on you - I think that's one of the big issues - blaming and fear of God.

Pain, in its physical, emotional and spiritual manifestations, was reported as a major issue for many patients. An administrator in HP and a social worker in HJ described these manifestations.

> Most frequent and most important at some point: fear of pain. Not just fear of physical pain but the fear of the things that come along with pain. The loss of control, feeling that there's no end to it, that it's going to affect their relationships with others...Pain can show a person's anguish that life had no meaning. Anguish can contribute to physical pain.
>
> Most of my patients are terrified of suffering; pain and suffering...I think there's also emotional pain...Holocaust survivors have emotional pain. How many people have I talked to that say there is no God; no God could be that awful.

Unanswered "spiritual pain" among people with Alzheimer's disease was described by a nurse in HJ.

> There's physical, psychological deterioration, and spiritual pain that is rarely addressed with Alzheimers patients. They're nonverbal, retracted into wherever they are inside...That essense that is the spirituality of the person is still there, and probably is crying out.

A patient interviewed exemplified many of the above issues including pre- and post-death anxiety, fear of pain and the loss of relationships. This 62 year old, single woman

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identified herself as an atheist and saw this as a strength: "It helps me get through on my own rather than depending on people." This patient expressed fears regarding the dying process and after death. An intelligent woman, she took pride in her significant career accomplishments. She was terrified of losing her cognitive abilities as a result of cancer in the form of inoperable brain lesions.

> I stop talking then I forget what I was gonna say...that bothers me...when I lose my train of thought. I understand with Alzheimer's you're not aware of what's happening to you. In my case right now I know what's happening...I feel that I'm losing control and that's very frightening.

She and her sister had developed living wills which clearly ruled out "heroic measures" and stated their desire to be cremated. Beyond these things which she could control, she freely admitted her "anxiety and depression." Death for her meant separation from her twin sister with whom she had lived her entire life. She shared:

> We do talk about dying; that's frightening. And being twins makes it even harder. Being twins, **identical**...She's always depended on me and I'm depending on her...I just don't like to see her by herself. And I don't like to see me by myself. We've always been so close.

Death signified "being alone, **totally alone**." The interviewer remarked on the internal strength she displayed through her lack of denial, her future planning and her willingness to look at death even when she has no pictures in her mind or beliefs about what will happen to her beyond "being totally alone." It may have been this remark or the nature of our conversation which was philosophical at times. But after awhile, she sat up on the couch, looked intently at the writer, raised her voice, and said,

> I'll tell you, I think you've been very helpful in terms of new ideas for me that I've been thinking about...it just gives me a different slant on things.

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In spite of her fear of separation from her sister and the prospect of the total unknown following death, she said: "I hate to say this but it sort of gives me an idea that this might not be a bad way to...die."

Exceptions

Notably, one or two respondents in each agency expressed surprise at the lack of fears or concerns among many of their patients.

> There are seldom, contrary to expectations, any specific religious needs. No one says, 'If I went to all the high holy day things, kept kosher, this wouldn't be happening to me'. All the formal trappings of organized religion are seldom an issue.

In HP a volunteer with 15 years of experience working with dying people explained this lack of fear, saying that by the time she becomes involved with hospice patients, they are very close to death and have, perhaps, already resolved these issues. The writer observed that these particular respondents have well-developed belief systems and are at peace with death and dying issues themselves. Perhaps they convey this peace and comfort to their patients.

Religious, Spiritual Resources

Religious Resources

Similar to religious needs, religious resources are divided into beliefs and practices.

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Religious Beliefs

Most often cited as a religious resource was a "strong faith," particularly faith in a highly desired afterlife. Two volunteers in HJ and a nurse in HP looked at this "faith" from different religious viewpoints.

> A lot of people deal with their death by having complete faith that there is life after death and that there's going to be a better existence after this one.

> Non-Jewish patients did not have as much a problem with a spiritual realm of being. A lot of black Christians talked a lot about Jesus, 'Come home to Jesus'.

> I've always been fascinated with the black Baptist community - that fundamental faith...I think it's just a blanket belief that there is a God, a heaven. They will be with their loved ones.They know that someone's gonna come for them.

Several respondents noted a strong belief among Christians and Jews in a personal relationship with and the presence in their lives of their God. A nurse in HJ explained the impact of this relationship.

> The belief that some people have in God is enormous. I really believe that it can move mountains, help people survive enormous devastation.

Finally, some patients possess an assurance that their life, and therefore, their death has meaning. A spiritual staff person in HRC described this attitude.

> ...belief that there is a purpose in life; that there is meaning for that person to have existed. They've lived a good life; had a good marriage; loved their spouses; brought up terrific kids; they're going to the good place. They **know** it; there's no question about it.

Religious Practices

Patients' current and past religious practices were often cited as resources. A social worker and a clergy in HJ and a volunteer in HRC gave examples.

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> Tried and true resources - people pray, read the Bible; if affiliated with church, will speak to rabbi or priest, receive communion.
>
> Those who are Jewish are familiar with special prayers we have, reading the Psalms. Things that people have done regularly and they like to call upon and continue to do if they are religious. Holding religious objects - a star, a cross. Particularly people who are not observant throughout their lifetime; they'll still have a little book of Psalms, not to read but just to hold and keep in the room with them. Attending church and synagogue services.
>
> Some people have felt very good that they have been steady in their religion. They went to church all the time, they did all the right things, and they seem to feel that this is sort of on the good side of their chart.

It was this history of religious practice which a surviving father believes sustained his young son who died of AIDS in HP.

> Being a part of the Christian community all his life; it was a natural part of his growing up. Sunday morning was to go to church. He maintained that on his own and was very active in his church in San Francisco.

Several respondents cited the importance of patients' and family members' affiliation with a church or synagogue and the services provided by its clergy and laypeople. An administrator in HP and a nurse and social worker in HJ explained:

> ...it's the people: pastor, people from the congregation are supportive, volunteer, take care of each other...The support of others...that's what has sustained them most.
>
> My Christian patients rely on their churches; especially my African-American patients are associated with a church...The church is an enormous support. They have a personal relationship with their ministers...They also have church members come to their homes regularly to pray with them, bring tapes, play gospel music or church choir music.
>
> Clergy visits, prayer, sacraments especially in the Black and Pentecostal churches. They bring peace, healing. Church members also visit; the patient feels loved, connected.

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Spiritual Resources

Spiritual Beliefs

A number of respondents reported patients' faith and belief in some kind of spiritual afterlife unrelated to any institutional religious belief system. Social workers in HJ and HP explained:

> Knowing that they are going to go to a better place without pain. Most of my patients who know that conceptualize it as pain-free and suffering-free. And to rejoin those spirits of their loved ones.
>
> The fact that there will be a reunion. This is not a forever parting; they will connect again...there's forgiveness and mercy.

A social worker and a nurse in HJ explained how these beliefs are supported for some by faith in some kind of "other being" which provides an assurance that their lives had meaning.

> A sense of something greater than themselves or a sense of the divine. It varies and depends on how someone has incorporated spirituality into their life to begin with.
>
> I think it's comforting (for patients) to think that there's a being out there who can help through intercession or through prayers.

Many respondents did not refer to any specific spiritual beliefs but rather to an "internal strength" evidenced in the person's "acceptance" and "peace" in the face of impending death. A clergy and a nurse in HP and a nurse in HJ described these characteristics.

> There's a quietness...People who are very spiritual are those who can be very, very angry at things that they can't change but they're...still very centered and connected to what renews them...Whatever sense they have of the spiritual they say, 'I don't have to understand that. I can't fix or resolve or save it...' Able to acknowledge that life is hell, rude, untidy: and they own it.

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> They have a strong spiritual base. They have a great deal of calm about them...I believe it is their spiritual strength because even if they don't have a formal way of saying it, they're drawing that strength from somewhere (to) face death without fear.
>
> They gain trust within themselves; there's a feeling of completeness, peace about the person...Sometimes a sense of finished business.

A nurse in HRC described how "making spiritual choices," can refocus the person for the remainder of her life.

> At this point in their life, they're given another opportunity to change: to be more open, to be more trusting, to be more accepting. The bottom line being, to improve the quality of their life...Openness: 'How open am I going to be to this illness? Trust: 'Am I going to trust the people in my life...or am I going to push it away and live in denial for awhile'? Acceptance: 'How am I going to choose to think about accepting this; can I accept where I'm at right here, today? And the people who have a good level of acceptance and trust and openness do the best, because they can enjoy what they have in life right now.

Spiritual Practices

A clergy in HJ and a volunteer in HRC gave examples of the variety of spiritual practices used by patients and families.

> A lot of people call upon their own spiritual mentors, advisors. They practice meditation, yoga, music...art.
>
> A lot of people draw upon their **life**. They draw on the good things that they've done. Perhaps they were a good mother or a good father; perhaps they were very good at their job; and they feel very proud of that, and that gives them a lot of strength. When things get low, they sort of pull from that. 'I was a good manager, and I went every day, and I stuck with it.' And they know that if they can do that, they can get through this...They have to keep sort of reaffirming themselves that there was some meaning to their lives.

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Several respondents reported spiritual services provided by hospice. A nurse in HJ explained:

> Many of them have gotten support from the spiritual staff here, especially the rabbinical and Christian interns. I've gotten a sense that it's meant a lot to my patients to have these people visit them and talk about spiritual concerns and observe the holidays with them. In the case of the Jewish patients, they may not have had a formal affiliation, but they have the background and it maybe touches something from their childhood to have this young person light candles on Shabat.

One respondent, a spiritual staff person in HRC, considered open communication within a family to be a spiritual resource.

> ...the families that are able to open up and discuss the illness, discuss what's going to happen. Open communication is the strongest strength a family can have. Without that, there is total isolation on both sides; and it doesn't allow closure for the patient.

Discussion

Differences Between Patients and Families

No respondents drew clear distinctions between patients and families in their religious or spiritual resources. A few in each agency identified differences in religious/spiritual needs between these two groups. They attributed the variation to the differing present and future foci of the patients and families. Patients are concerned about and at times are obsessed with their current illness, the process of dying and the afterlife. Families are more focused on their current relationship with the patient, frequently expressing feelings of powerlessness; and fear for their own survival following the patient's death. A spiritual staff person and a volunteer in HRC explained:

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> The patients get more internalized, tend to back away, more with themselves. And the families get more dependent on you...Afterlife more prominent in person dying; not as verbalized in family-more concerned that relationships be there for the person.

> The patient is concerned with their family, but the family is more concerned with the patient...Their focus is the patient; the patient, of course, is mostly taken up with himself.

A spiritual volunteer in HRC described how these varied concerns become more pronounced as death approaches.

> The patient is usually more accepting of what's going to happen to them; it becomes more inevitable. They cannot ignore the symptoms...so their needs emotionally are not as much...the family's needs become more. The family becomes more frightened, more anxious; they don't want to see their loved one in pain. They don't know whether to hope the person will die...or will linger longer...You're still on the outside, waiting when you're the family. You just don't know.

Distinction Between Religious/Spiritual and Psychosocial

In a content analysis of spiritual assessments used in hospices Dudley, et. al. (1995) found that some questions could be interpreted as either spiritual or psychosocial in nature. Respondents in this study were asked to identify any differences.

Religious, Spiritual Needs

Respondents distinguished between religious and psychosocial needs, referring the former to institutional religion. They did not separate spiritual from psychosocial needs, viewing them as interconnected. Echoing other respondents, a volunteer in HJ described how the spiritual dimension encompasses the dying person's psychological and social needs.

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> All needs, if you strip them down to their essence, are spiritual...We have a need to be loved and to love, a need to feel part of the human community. I think as we approach death, those needs become more desperate if we haven't met those needs before.

A clergy in HJ differentiated between psychological and spiritual depression, viewing the latter as more all-encompassing.

> When a patient is saying things that are out of touch with reality, I would refer to a psychologist. This would be psychological depression. There's also a spiritual depression when a person is out of touch with their ground of being. There's a spiritual void; cut off from others. They feel that there's no meaning in their life.

Religious, Spiritual Resources

Respondents differentiated religious/spiritual from psychosocial resources, pointing to the unique qualities of the former. Religious/spiritual resources "go beyond" psychosocial resources and support systems in several ways. First, these resources are **transcendent**, as described by a clergy in HRC.

> I think there's a transcendance about spiritual values that rises above all the others and in some way can be the driving force for all the others. Someone once said, 'Spiritual values are like sound waves in the air. They're there, but only the people can hear them who are fine-tuned.' I think it's that fine-tuning process, that ability to zero in, to pick out and affirm the important things that you feel have carried you through what you've been through all your life.

A nurse in HP described how this transcendent quality can be experienced in a conversation.

> A knowing beyond what we know as our senses. I've had conversations where neither one of us has said a word.

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Second, spiritual resources "go beyond" psychosocial resources in the **meaning** they convey to the person, as described by a spiritual volunteer in HRC and an administrator in HP.

> I think it's so important to them; it's so meaningful to them, and that makes it spiritual instead of social. I'm not sure, especially when you're facing death, that anybody goes back and considers anything social very important.
>
> I would say social support is people who come to the house, bring a meal, run errands, do tasks. But the spiritual part is what's behind that giving. Knowing the person is there for you; their presence. People are not going to abandon you because you're sick. A sense of security.

A clergy in HRC explained that for some, this meaning is buttressed by the belief in a "higher power."

> God is a very big part of that issue, however people perceive God...The reliance on a higher power, the ability to surrender, the ability to recognize my own powerlessness - all of those issues surface in peoples' lives and those are things that aren't picked up in the psychosocial arena at all.

Impact of Needs and Resources on Death

Religious, Spiritual Needs

A few respondents had known patients whose questions, fears and pain appeared to influence their approach to death. A nurse in HP shared her thoughts about this.

> I can see the difference in the kind of death experienced by somebody who is at ease with those questions versus someone who has not resolved...what those questions mean...Fear is a biggy - anguish and anger for those who have not resolved it. There is the inability to accept it. Can't prove it, it's just a sense, that it affects the response to pain...To me, the (patient's) pain takes a different quality for someone who has that question in their mind.

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A nurse in HP described a woman who was in tremendous pain; her body was "rotting away" and yet, she was terrified of death.

> Some people never get over fear. Some bodies go way beyond what the body can tolerate. I directed her to 'go towards the light' but she could only see (a) dark hole. Tried to dive into it but unable and pulled herself back. Believed (she) was not a good person and was terrified of death. Difficult for her to let go.

Observing that "most frequently people die as they live," a nurse in HJ related that some patients, "...still fight to stay here. (They are) very angry about being ill/dying; they go down fighting."

Religious, Spiritual Resources

Weisman (1972) sought and found among terminally ill people "meanings of death" other than a universal evil, always to be feared, and never an acceptable outcome. From these findings he articulated the concepts of "hope" and "acceptance of death."

> Hope means...we have confidence in the desireability of survival. It arises from a desireable self-image, healthy self-esteem and belief in our ability to exert a degree of influence on the world surrounding us (p.20).

Acceptance of death: "Mortality is a dimension of living, not merely a negation or end-point that cancels out everything" (p.21). Two patients interviewed in HRC expressed and embodied hope, strong self-esteem and an acceptance of impending death. An elderly, devout Roman Catholic woman said:

> I think it's so important to love yourself. I stress that with my grandchildren - 'God made you good'. I believe my spirit can't die; it's too wonderful. (I have) no fear of death. Very strong feeling of the hereafter. It's a personal, private meeting with the Lord.

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A woman in her 40's who was dying of cancer reported that:

> I think positive. Thinking positive is uplifting; think negative, (and) everything goes down hill...I wish death would come and take me...I welcome it. I'm ready but God ain't. My (deceased) father has a place for me over there.

Kemp (1994), O'Connor (1993) and Corr (1992) note the role that humor plays in coping with terminal illness. "Humor doesn't deny the hurt, it is a vehicle through which anger and defiance and pain can be handled" (O'Connor, p.139). The two patients interviewed each demonstrated a sense of humor and a transient perspective on their mortality. After explaining her beliefs in the afterlife, the elderly woman smiled and said,

> On the other hand, if what I've been taught is wrong and a fairy tale, I'll just go into a nice sleep and won't feel any emotional or physical pain.

The young woman who had lived with uncontrolled epilepsy almost her entire life pointed to her body and said, "If I come back, I'm not coming back to this old model."

Viewing death as "a confluence of biological, social and psychological factors," Weisman (1972) developed the idea that a person participates in her dying process, ideally reaching an "acceptable death." Others have developed stage-based and task-based theories of dying (Kubler-Ross, 1969; Corr, 1992), and the religious or spiritual dimension has been factored into the dying process. Today in hospice one frequently hears accounts of a "good death" or the "spiritual death" of a patient who "faced death with dignity," "willed herself to die," or "was at peace in death." A nurse in the residential hospice in HRC shared two different "spiritual deaths."

> One was a very spiritual woman, very much in acceptance of what was happening, very much in control up to her last breath...On the other hand, the

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> death of a very quiet, gruff man was unique in that he told his sister, 'I'm going now', and within the hour he died. That was his way of being in control until the end.

A nurse in HP recounted a woman's spiritual struggle and resolution.

> She said, 'God is getting me'. She had a lot of problems with pain management. I knew no matter what we did, we weren't going to control her pain with medication. She had become estranged from her family, but in the last few weeks her family was there for her. Then finally we were able to control her pain...The day she died, she was very restless, 'wrestling with the angels'. Her sister took her in her arms. The patient died peacefully.

Many respondents told of the positive impact that patients' religious or spiritual belief systems and practices had on the dying process and death. Two spiritual staff and a clergy in HRC gave examples of the sustaining power of religious beliefs and practices.

> These people who profess to have faith appear to have...I wouldn't say a much easier time, (but) less difficulty maybe in their journey and what they're enduring...They are willing to say, 'Well, this is it. Whether it's God's will or not, this is it and I'm going to use my faith in God, my belief in God, my love relationship I've had with Him before to deal with this.'
>
> She was active in church until she became ill. She had a strong faith and was able to accept where she was...I questioned her about life after life. She said, 'Very definitely, yes. It's called Heaven and I'm going to go there shouting!'
>
> People who have a strong personal relationship with God, Christian or non...can face death, any crisis ahead...I've seen people face death as calmly as if they were going to go to bed for the night.

Two nurses and an administrator in HP described manifestations of these resources.

> There can still be pain, and will require medication but it's more the ability to see it as transient. To accept that it will be over in due time and more ability to ride with it.
>
> Strongly religious people have a lot less fear of dying; it helps them go through the grieving process faster...It seems as though a good percentage are much more adjusted to the idea about the end. They're not so ambivalent about dying. There's a real peaceful resignation in the way they look - not a

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> weakness - but they're resigned to the situation, as well adjusted as can be: a calmness.
>
> I've seen people become transformed and become beautiful. I think of the most hardened, feisty old guy who all of a sudden wants to make up with his brother or welcomes his son back.

Derrickson (1996) discussed a spiritual process which facilitates disconnection from this world and reconnection with "the spiritual world which is our true home" (p.23). Many workers shared stories of patients with strong beliefs in an afterlife and in the "spirit world" having visions of and conversations with deceased family members, friends and "God." A volunteer and a physician in HP and a nurse in HRC related some of their experiences.

> In the end she was feeling closer and closer to those people who had been dear to her who had died before. She really felt that particularly, her brother was calling to her...She had her brother reaching out to her.
>
> I've seen some people that have had experiences with things happening in the room that none of us can see. I've seen people look beyond you as if there's a light over your shoulder and a big smile is on their face. There's peace there.
>
> At one point I remember that she was looking off, and I really felt that she was looking at someone else that was waiting for her. I really had that strong feeling...She died peacefully through the night.

A family caregiver in HRC reported that her daughter "had no fear of dying," having seen and talked to her deceased father and knowing that she would be reunited with him "on the other side." A nurse in HJ explained the current undrstanding among spiritual care providers of these supernatural experiences.

> We no longer use the word hallucinate...We say that people will talk to and see loved ones who've gone on before. It may have a physical, chemical cause

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> but they still see them. It is as if someone's there to say, 'Give me your hand. I'll help you cross to this peace.'

Respondents were deeply inspired by the ability of some patients to support others even as they were actively dying. A nurse in HP explained:

> Those that do have a strong faith are so much more at peace and able to give to those that are hurting and being left behind, rather than be concerned about themselves.

A volunteer in HP and a nurse and two volunteers in HJ described some of these patients.

> My son never had those fears about where he was going to go. The night before he died, we talked about that. He said, 'I wish God would take me soon; I'm becoming a burden for you people...I want to go home.'
>
> She was Lutheran. A simple faith. Her life was right with God; this brought peace. I guess I was part of that at the bedside. I valued her through it, from diagnosis to death.
>
> She was Christian, in her 30's, had cancer and was leaving 2 kids and a husband. She told her family, 'I'm gonna be allright; I'll be with God; I'll see my other relatives'.
>
> There was an AIDS patient everybody remembers who was actually trying to console other people...He tried to tell us he was completely prepared for it and he's going to his maker.

Impact of Resources on Survivors

Members of a bereavement support group which the author observed in HP frequently raised spiritual issues and shared their experiences. Two women spoke of dreams, visions and conversations with their deceased spouses.

> I do have a relationship with him and that's not dead - will never be dead...Last time we talked, I was very angry with him; needed to know things

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> from him - the whys. Was very frightening but comforting to know (he) was still alive to me that way. Still so real in my life.

Several shared religious, spiritual activities which provide comfort.

> Through church, prayer, meditation, know inner level of quietness; very helpful...At times have asked God, 'Just take me, embrace me, make the pain go away'.

> I go to church, sometimes talk to God, at times (I'm) angry. I say, 'Be with me; touch me.'

All members agreed with one woman: "If it weren't for these dreams, talks to God and my husband, I wouldn't be coping as well."

Cross-Agency Analysis

Analysis of this data revealed similarities in all three agencies' descriptions of the content of religious and spiritual needs and resources among patients and families. However, there were differences in who discussed the needs and in the relative focus on "religion" or "spirituality." There was no such difference evident in the discussion of these resources. There was little variation across agencies in the other findings, including the impact of these needs and resources on death.

Religious, Spiritual Needs

A general concensus was apparent regarding the difference between "religious" and "spiritual" needs. Respondents associated religious issues with the beliefs and practices of institutional religion, and these vary with different religions. There was also agreement on the major spiritual issues: fear of dying and after death; concerns regarding relationships

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and abandonment from other people and God; the meaning of their lives; and varying dimensions of pain and suffering.

In HRC it was primarily clergy and members of the spiritual department who discussed these needs. In the other two agencies a variety of staff and volunteers participated in the discussion and they identified spiritual needs more frequently than those with a religious base. Respondents in HJ also associated particular religious needs with patients' and families' religious affiliations (Jewish, Protestant, Roman Catholic), more than respondents in HRC or HP.

Religious, Spiritual Resources

Proportionately equal numbers and types of staff and volunteers in all three agencies identified religious and spiritual resources. Primary among the religious beliefs noted were a "strong faith" in a desired afterlife and belief in a personal relationship with the Judaeo-Christian God. Prayer and reading the Scriptures along with active affiliation with and the support of a religious community were the religious practices most often cited. Many patients hold beliefs in a desired afterlife and in an "other being" but do not associate these with any religion. Deriving "spiritual strength" from their own lives and other "spiritual people" including hospice, these people achieve a "peace" in the face of death. The types of spiritual resources used by patients and the spiritual services provided by HP and HJ were somewhat more diverse than those in HRC.

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Other Findings

A few workers in each agency identified differences between patients and families in their religious, spiritual needs based on their differing foci of concern. No one reported any meaningful difference between these groups in their religious, spiritual resources. Although a few drew distinctions between religious and psychosocial needs, respondents generally viewed spiritual interconnected with psychosocial needs; or they described the spiritual as encompassing other concerns. However, workers in all three agencies did differentiate religious/spiritual from psychosocial resources, referring to the transcendent and full-of-meaning qualities of the former.

Few respondents from any of the agencies described any relationship between a patient's religious, spiritual needs and the quality of his death. In contrast, the vast majority in each agency shared stories of the sustaining power of these resources in patients' deaths and in the survivors' lives.

Conclusions

The types of personnel discussing religious, spiritual needs and the variety of available spiritual resources were somewhat more diverse in HP and HJ than in HRC. The level of division of responsibility for providing spiritual care and the diversity in religious, spiritual affiliations could explain this variation. In HRC only the Spiritual Department is responsible for spiritual care while this responsibility is shared in HP and HJ. The affiliations of workers, patients and families in HP and HJ are also more diverse than in

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HRC. In the assessment of need, the psychosocial is interconnected with or encompassed by the spiritual realm. However, when considering the patient's and family's resources, the spiritual clearly becomes ascendant over the psychosocial.

The most meaningful relationship discovered in this analysis was the connection made by these spiritual care providers between the religious, spiritual beliefs and practices of the patient and the quality of his dying process and death. Patients who express or evidence a "deep faith," a relationship with a supreme being and/or a belief in an afterlife or "spirit world" are able to maintain realistic hope and positive self-esteem. Forgiveness, reconciliation, saying good-bye – current relationships receive needed attention; and the dying person prepares to reconnect with the spiritual world through visions of and conversations with those "on the other side." These vivid accounts of patients' "spiritual deaths" provided some of the most moving moments in interviews with the workers. While giving detailed descriptions of the experiences with their patients, they appeared to relive the deaths and reported feelings of "exquisite joy" and "a transcendent serenity."

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Chapter 7: Spiritual Care

Introduction

The purpose of this study was to conceptualize the elements of "spiritual care" by grounding its provision in the human experiences of hospice staff and volunteers serving terminally ill patients and their families. The foregoing chapters presented the following meanings or contextual dimensions of spiritual care: agency spiritual care cultures; definitions of terms; staff and volunteer dynamics related to work with dying people; and the religious, spiritual needs and resources of patients and families. All of these underlie the actual rendering of this service.

The respondents' descriptions of spiritual care fall into the following categories: principles for the appropriate approach to spiritual care; descriptions of their care activities; and patient and family responses to this service. A spiritual care process emerged from analysis of this data. The chapter concludes with a cross-agency analysis of the findings.

Principles of Spiritual Care

The hospice philosophy of health care is based on clearly articulated values: Palliative (comfort-oriented) care; treatment of the **whole** patient and family as a unit; affirmation of life, regarding death as a normal process; and emphasis on human values that go

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beyond the patient's physical needs (National Hospice Organization, 1992). The NASW Code of Ethics (1994a) presents clearly defined principles for the engagement of clients preliminary to the provision of service. These guidelines reflect the basic values of the profession: respect for the person's individual dignity, a non-judgemental attitude and client self-determination. In its policy "End-of Life Decisions," the key element is client self-determination (NASW, 1994b). Wesley (1996) calls for a balance between client self-determination and the general welfare of society when working with patients and families regarding end-of-life decisions. Clearly, the care of people with terminal illness raises a host of ethical issues. The service providers in this study articulated four principles they follow in rendering spiritual and other types of care.

Preparation

Workers frequently prepare themselves mentally and spiritually prior to seeing their clients by praying, listening to music or "sitting by a stream." A volunteer in Hospice Protestant (HP) said: "I pray a lot before I go to the home...'I'm needed here, please put the right words in my mouth'."

Openness

The spiritual care provider makes herself open to whatever the person wants or needs. A spiritual volunteer in Hospice Roman Catholic (HRC) and a volunteer in Hospice Jewish (HJ) described this approach.

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> You don't go in with any set agenda, because the patient sets it. You have all the time in the world.
>
> You have to be an Etch-a-Sketch. You have the two knobs but the patient has the picture to draw.

"Start where the client is" (Goldstein, 1983). A volunteer in HJ applied this social work standard to her spiritual work.

> I think of it primarily as trying to be wherever that person is. I'm willing to do whatever they want to do. If they want me to listen, I listen; talk, I talk; read Scripture, I read Scripture. I go in and sing to patients if I think that's what they want. I try to be open and let theSpirit work through me. Sometimes I get in the way of the Spirit. I think what's most important to people is a willingness to be with them wherever they're at.

This openness allows the spiritual care provider to enter the other person's world "...to perceive the world from within the client's own frame of reference...in a collaborative search for meaning" (Goldstein, p.271). For a spiritual care provider, this translates into perceiving the person's spiritual world. A priest in HRC discussed this.

> The key to getting inside the spiritual world of a person is to find out what's the key (chuckle). If the person going in there can bring themselves into that world of the individual and develop an appreciation for it, it brings them into a bond with that person.

Acceptance

Mauritzen (1988) proclaims a "towering ethical imperative" when working with dying people:

> The patient and family members have the right to expect total acceptance of all they stand for as people. This applies especially to everyone's spiritual beliefs and preferences...Thou shalt respect! (p.119).

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The most often and most strongly emphasized principle was an unconditional acceptance of the person's being and feelings. Many referred to a non-judgemental, objective attitude which conveys respect for the person and validates her feelings, whatever they may be. A spiritual staff person and a spiritual volunteer in HRC and a clergy in HP explained:

> Acceptance is vital...Your face can't show any judgement. You're not there to judge their life; you're there to accept their life, to validate their life and if they're having trouble finding meaning, to guide them in that process.
>
> ...I can be objective; don't know the history of what they're telling me, so I can take them just as they are and they know that. They are who they are at that moment to me, and that's all they ever have to be.
>
> ...unconditional acceptance; my attempt to fully understand the person I'm with; to be able to receive anything no matter how disagreeable it might be.

Spiritual care providers demonstrate this respect by assuring that patients and families maintain control over their decisions, their beliefs and their lives. A volunteer and a nurse in HP described this.

> They must be in control and know that you're there to help and support them when they reach out to you. Don't interfere with their past...except in the sense of being with the person to listen to them and hopefully hearing beyond some of the words to what their real needs are.
>
> I think more than anything it involves a sensitivity to the family's belief system and supporting that...I develop a very strong relationship with my families...an empowering relationship...by respecting them...I think you need to have that sensitivity to their spiritual needs in order to be healing in this transition.

At times there is a desperate wish to help before it is too late; so much is at stake (Mauritzen, 1998). Responding to the anguished "why" questions of people in psychic and spiritual pain presents the greatest challenge for some. A spiritual volunteer in HRC and a minister in HP explained:

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> Looking for answers (is the) most challenging part of hospice. You need to be able to turn the question back to the patient so they can answer their question from within themself.
>
> My biggest struggle is to avoid false reassurance. We must give them permission to feel what they're feeling. Learn to affirm whatever can affirm in the patient in spite of the horrible things (they) may have said or done.

Kemp (1994) called this "...watching faithfully with the patient...in the desert of no faith, no hope" (p.33). A nurse put this respectful attitude succinctly: "It's their death."

Self Awareness

Zerwekh (1993) identified "personal grounding," or awareness of one's personal philosophy as one of ten competencies of "hospice experts" (p.27). Social workers in HP and HJ cited self-awareness as a necessary preamble to effective spiritual care.

> As a social worker, I will use my self in whatever I do...I really think the sense of knowing yourself and how you feel about most of this stuff is the big key. If you're comfortable with it, you can cash in on it.

A social worker in HJ described how she has grown in her self-awareness through her spiritual insights.

> I guess my problem in doing this work is sometimes I think I've done the wrong thing or I haven't helped enough, or the right way. Or I didn't get done the work that they were working on before they died...That was a real source of frustration...and sadness for me when I first started work...Now I feel that it doesn't all need to be resolved in this lifetime.

Spiritual Care Activities

Recently, a few scholars have begun to identify components of spiritual care in a variety of forms (Derrickson, 1996; Jones and Churchill, 1994; Kemp, 1994; O'Connor, 1993;

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Zerwekh, 1993). Descriptions of spiritual care in this study involve multifaceted expressions through non-verbal and verbal communication, creative therapies, specialized techniques and role enactment.

Non-Verbal Communication

Presence

> Whoever would be a companion to the dying...must enter into their darkness, go with them at least part way along their lonely and frightening road" (Cassidy 1992, p.6&7).

The importance of presence, being with or watching with the dying person is frequently noted in the hospice literature (Kemp, 1994; O'Connor, 1993; Zerwekh, 1993). Presence is a service of **being** more than doing or problem-solving. A nurse in HRC with many years of experience in acute care shared:

> I have learned that (I don't) have to do something or get patient to do something. All I have to do is show up and be present.

Presence involves being physically with the suffering person, often without words. A nurse in HRC explained that: "I'm there for them, I'm totally focused on what's happening for them...just really, fully there." Jones and Churchill (1994) offer the archetypal image of the "wounded healer" (Nouwen, 1975) to convey the demands of this type of presence. As the "wounded healer," the doctor, social worker or nurse is a "soul-friend" who lays aside her professional competencies and tools,

> ...and approaches the person with empty hands. We care, listen, share, respect, and hurt in vulnerability and powerlessness with another (p.28).

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Stating that "Powerlessness is spirituality," a priest in HRC explained:

> You get to a point where there's nothing you can do except learn how to be, whatever you need to be for that person.

"For presence to be of benefit, its intervention must be done with compassion" (O'Connor, 1993, p.139). A clergy in HRC defined compassion and a volunteer in HJ identified the primary task of a volunteer.

> The ultimate spiritual value is compassion...Compassion means the willingness to suffer with those who suffer, to feel their pain and to be a part of it.

> I think the major thing that volunteers do is a willingness to be present in the face of suffering and/or sickness.

Given these daunting demands on the care provider, her willingness to return again and again to the side of her patient conveys a powerful message. A nurse in HRC explained:

> ...sometimes you just keep showing up and you just keep caring...the perseverance - it really works.

Touch

Being "fully present" with a person is best communicated at times through touch by holding, stroking or rubbing. An aide in HRC and a nurse in HJ gave examples.

> Sometimes when you sit with them, hold their hand, talk to them or give them a hug, you really feel like you are helping them out spiritually...When you have someone to hold your hand or put their arm around your shoulder, it seems to make it a little better.

> That's where I sit and hold a patient...This gives them tremendous comfort for some reason. (I) also teach the family to sit very quietly and just hold the patient.

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A nurse in HP still engages in touch, "Even if they're in a coma. I talk to them...I'm just there."

Listening

"Actively listening is what my major spiritual role is" according to a spiritual volunteer in HRC. This provider exemplifies an old social work practice principle recently given new expression:

> We must enter into a collaborative search for meaning with our clients and listen to their voices, their narratives, and their constructs of reality (Hartman, 1992, p.484).

Spiritual care providers convey an openness to and acceptance of people through active listening. A spiritual volunteer in HRC explained:

> I listen, that's number one; that's the biggest thing that I do...I let them hear back how good they really are. I just reflect back what they're telling me, and I affirm what they're telling me!

Through these forms of non-verbal communication, providers "enter the other person's world," make powerful "connections with others' spirits," discern sources of pain and provide comfort. A volunteer in HP described how she spent time with her patient and learned of her needs in the process.

> The woman loved to sit outside...We would sit there sometimes for 3 hours at a time, holding hands, looking at the birds, then every once in a while she would ask, 'Now what do you think happens to the soul after death'?

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Verbal Communication

"Dialoguing is vital to spiritual caring" (Zerwekh, 1993, p.28). Discussion of unresolved spiritual concerns involves intense dialogue about spiritual beliefs and experiences. A minister in HRC explained the goal of this dialogue.

> If we can resolve those issues and uplift their spirit, we can give them better quality of time...We can use that time to resolve the issues and...allow the person to die not only with dignity but in spiritual peace.

Fear of Dying and Death

Dying is said to involve "essential loneliness," "darkness," "mystery" and "a lonely, frightening road" (Zerwekh, 1993; Cassidy,1992). Spiritual care speaks to the profound fears around dying and death, sometimes from one's own beliefs. Two nurses and a social worker in HP gave examples.

> For some, you need to let them off the hook; it's so important for them to hear that God will forgive them, if that's where they're at...I provide reassurance so that the patient can be at peace and the families can cope.

> They will start talking about feeling badly that they have no thoughts of an afterlife, heaven or hell. They ask 'What do you think'? I tell them, 'No matter what, you will go on in memories of people; your ashes will be part of the soil.' I think for those kind of people it's reassuring.

> We have death as transformation discussions: 'Nothing really is lost. People are preparing for a transition; not in body anymore but still in some kind of form'. One person called it 'recycling.'

Speaking from his own experience with his deceased wife, a volunteer in HJ related a conversation with the daughter of a patient.

> I told her about my experience and what she could expect. 'You have to roll with the punches. And you have to learn to say to him that it's OK to go'...It's

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> very hard thing to accept. I found it difficult until I could bring myself to say it. When I did, my wife relaxed. She knew I was there. I spoke to her; I'm sure she heard me. (tears)

Religious Beliefs

A person's religious beliefs may be a source of consolation or distress. Care providers exercise particular caution in knowing the difference and when to share their own beliefs. A spiritual staff person in HRC related the following story:

> I knew a lady, in her 40's with Lou Gherig's disease, with two teenage sons and husband. It was very difficult for me. How could I read certain scripture about God's goodness, about Him doing things for you and healing? I had to be careful about choice of scriptures. Meditations for the sick were good to read to her. (I) told her that God loves us and allows us to be that way with Him. I tried to be where she was - a lot of praying and no results. (I told her) 'It's allright to feel that God is letting us down sometimes or doesn't understand, or we don't agree with Him'.

This same care provider went on to say:

> Sometimes I say to the patients...'You know, a lot of people feel anger with God. They rave and rant and shake their fist at God. Hey, God can take it; God has big shoulders'.

The most often cited religious-based belief thought to cause spiritual distress is the conviction that the illness is a form of punishment by God. A social worker in HJ and a minister in HRC described how they handle this situation.

> Gay patients with AIDS who feel their illness is a punishment for being gay (is) very painful personally. I try to find a way to reframe the issue, but acknowledge it's their beliefs.
>
> The first feeling is that you want to change that. But that's against my policy. The unfortunate thing is if a person was raised with a religious hard line, they've never changed. God was an ominous person, more judge than savior.

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Guilt and Anger

Spiritual care providers help people resolve feelings of guilt and anger. A nurse in HP told about a "deeply religious," Christian woman who was clinging to life for more than a year.

> She was in really bad shape when she was admitted (to hospice) and over the course of a year we didn't know what kept her going...a wonderful woman who did everything she could for her kids...You would have thought...she would have been at peace and died...You always had the feeling something else was going on...Apparently she had had an abortion many years before and had never told anybody. Her husband was the one who took her for the abortion; he left her soon thereafter. She told me everything about the abortion in great detail. I told her she'd see the baby in heaven and welcome her into heaven. She seemed relieved with the idea of meeting with the child in heaven. I also reassured her that God understood and would not punish her. Later she told each of the children about the abortion. Less than a week later she died peacefully.

Creative Therapies

Spiritual care providers often provide or engage in ritual, music, prayer and reading. Jones & Churchill (1994) called these activities "creative therapies" (p.32). A social worker quoted Brown (1991): "When words fail, music speaks." A volunteer in HJ shared:

> I try to make a physical connection, perhaps through music. This can provoke an amazing response. It's a way of establishing a very emotional connection. It's easy to show emotion with music. You're bringing this up from yourself to say to another person, 'I feel this also'. It establishes a bond in some way.

Prayer, reading and other activities provide comfort. A volunteer in HP and a social worker in HJ provided examples.

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> If (the) patient is close to death, I stay with them until they pass. Pray with family member. Attend wakes and funerals of those I know, read scripture at funeral sometimes. Make bereavement calls afterwards.
>
> I help the person become more calm; I call upon the spirit. I may pray for them when I'm there. Sometimes read meaningful passage of the Bible or other books.

A nurse in HJ described the use of pacing with her prayers.

> I will use a prayer that people know by rote – with Jews it's the Blessing Prayer – and simply say it quickly and then temper my pace. Their breathing will relax; their blood pressure will go down.

A nurse in HJ described how patients experience the power of corporate ritual in an in-patient hospice.

> The nurses gather around the bed when a patient is dying...Use tapes - chants, verses, including Yiddish. Gives a sense of completeness, peace; the person's spirit was also tended to.

A social worker in HJ uses corporate ritual to make connections with her patients.

> When people observe their rituals, I participate in them...I connect with the person's spiritual self when they share their own experiences with me.

Specialized Techniques

Several respondents reported using particular techniques for some of which they had been trained.

Lovebombing

A nurse in HRC described "lovebombing," a technique similar to confrontational methods used by families with alcoholics.

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> I use lovebombing in a crisis...I used this with a very angry 38 year old motorcycle guy...I kept telling him he had to let the love of people into his life, to let go of the anger. One week-end he was...verbally abusive toward people who loved him. I instructed everyone who entered his room to say: 'I love you, (name). I know you're real angry and scared, but we're here for you. And God loves you; no matter what you're feeling, God loves you'.
>
> I also instructed people not to react emotionally to whatever he said and to leave the room immediately for own emotional safety...Every person that went into his room that day said that to him, and the next day he greeted me with 'I love you'!
>
> That's lovebombing...(It) requires lot of emotional and spiritual preparation, because it's like an assault. In the scripture they talk about 'putting on the armor'...If the walls get really high, that's the only thing I've found that gets through.

Life Review Therapy

Life review therapy (Lewis & Butler, 1974) involves reminiscing, reassessing, mourning, forgiveness, resolution, and reconciliation (Derrickson, 1996; Jones & Churchill, 1994; Zerwekh, 1993). To be therapeutic, it requires "a caregiver actively listening and bearing witness to another's story" (Lewis & Butler in Jones & Churchill, 1994, p.27). Life review can affirm one's past life according to a spiritual staff person in HRC.

> Where they grew up, the difficulties they had in their childhood...What they did for a living, education, how they feel about their marriage...I show empathy, and that they survived difficult time. 'It is a big deal; you survived that'!...That shows them their inner strength that they might not recognize.

A spiritual volunteer in HRC explained how it can also help the person look toward her future.

> A lot of people have... unfinished business...something maybe they've never come to grips with. Perhaps they've lost a child...Oftentimes it's death that they have never truly reconciled themselves with, and they need to talk about it, have it all come out, and then they can see it...the whole picture and be able to put it in perspective..and accept it and go on.

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Guided Imagery and Therapeutic Touch

> Healing is derived from the Anglo-Saxon word haelan which means to make or become whole. The healing process is the innate ability to integrate and balance body, mind and spirit (Mulloney & Wells-Federman, 1996, p.27).

Guided Imagery (GI) and Therapeutic Touch (TT) both evolved from ancient healing practices. GI is a cognitive tool, using mental images and all of the senses - vision, hearing, smell, taste and touch - to form a bridge between the body and the mind. Through the self-selected mental images, a person can communicate with the body's physiological processes occurring outside conscious awareness. In theory, the imagery serves as a powerful instrument for altering physiological processes, mental state, self-image or behavior (Achterberg, 1985). Lebaron (1989) contends that terminal illness presents an existential crisis of meaning and survival which may be more amenable to the use of metaphors and symbols, employed in GI, than it is to rational, verbal interventions such as psychotherapy. Schneider (1984) described the potential value of images in coping with "impossible" situations:

> It is the imaginative process that finds meaning where none seemed to exist. It is in their imagination and dreams that people can later see problems as challenges and explore the possible. (Fantasy) opens up the intellect, frees the spirit and challenges the individual to reach for greater fulfillment of their potential (Schneider in LeBaron, 1989, p.22).

LeBaron concludes:

> Patients who are struggling to experience life more fully need help in perceiving new meanings and potential in whatever life remains. Imagery may be unique in its ability to uncover and to encourage that hidden potential (p.22).

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A few workers described how they used GI to help patients relax, experience less pain and find meaning in their remaining lives. A social worker in HP explained:

> It's imagery tied into things I know about them; things that give them peace; things where they find meaning in life and where they find their greatest contentment. Sometimes I use religious imagery - see angels coming down.

This worker guided an architect to a place where he could be alone and at peace.

> 'You've designed your own sanctuary, (a) place where you will feel comfortable. No one will intrude or interrupt you here. You can go here whenever you wish.'

Therapeutic Touch is also a contemporary interpretation of ancient healing techniques, including the laying on of hands. Developed in the late 1960's as a nursing intervention, it is based on Rogers' (1970) Science of Unitary Human Beings which evolved from general systems theory and assumes that a person is a unified whole, characterized as a complex human energy field and in continuous, mutual interaction with his environment.

> Body, mind and spirit...are not separate substances or categories but rather different energy frequencies that are continually interacting. A human being is a complex, multidimensional energy system (Macrae, in Mulloney & Wells-Federman, 1996, p.29).

Disease, injury, pain or anxiety can create disturbances in a person's normal energy field. TT treats these disturbances through a consciously directed process of energy modulation, using one's hands as a focus. This is done by holding and moving one's hands about two to four inches from the person's body, from head to foot, gently attuning to the patient's condition by becoming aware of differences in sensory cues perceived through one's hands. According to Kunz (1985), conscious awareness of this healing energy and the

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ability to facilitate its flow within oneself and within others arises through the spiritual dimension of human experience.

Several workers in this study described the visible effects of this technique - the physically relaxed body; the slow, deep breathing; and the calm, contented look on one's face. A surviving spouse in HP told about the use of GI and TT with her husband. The social worker had used GI several times and the patient "saw" himself hunting (his hobby) and "saw" his deceased mother and grandmother waiting for him. When he was in a coma, the worker used TT. After she had finished, he sat up, said to the worker, "Tell my wife I love her," and died within the hour. The survivor was impressed with the worker because her husband was terrified of dying and these techniques "...seemed to help him face death with less fear."

Role Enactment

Derrickson (1996) describes through patient anecdotes a "definable, spiritual process that allows us to disconnect with this world and reconnect with the spiritual world which is our true home" (p.23). Through the many varied activities described above, spiritual care providers accompany the dying person on this journey. Some of these activities, it became clear, involve the enactment of intermediary roles variously called "an instrument of God or of the Spirit," a "midwife" or a "spiritual linkage." Some roles are based on religious entities or the religious community. A minister in HRC and a rabbi in HJ shared:

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> The last thing I try to do is to let them know that, regardless of what's happening to them, whether they want to believe me or not, I represent the love of God. I'm just an instrument, but that's why I'm here. I have no other reason to be here but that God has sent me.
>
> When a religious leader comes to visit, there is a sense that God still cares, religion still cares and the community still cares. Hopefully, that's the healing we can give a patient...'We're still with you.'

Other roles have no association with religion. Nurses in HP and HJ described some these roles.

> I think I'm the link with the 'here and now' that accepts the link with the next phase...My presence is making the link acceptable sometimes by giving the OK to let go from this phase.
>
> It's not a healing of the body necessarily but it's being the conduit for some force or energy that is outside of me and the patient to help ease the spiritual part of the patient.

A social worker in HP differentiated the roles of "spiritual counselor" and "spiritual linkage."

> Spiritual counseling involves verbal question/answer; the talking about spiritual/religious issues. Spiritual linkage is being in the midst of, helping person connect to (the) spiritual dimension. I have worked with patients taking them to the void, the tunnel, showing them the way with guided imagery. (I) have never taken them to the end (of the tunnel).

This enactment of an intermediary role introduces a deeper dimension to the care relationship which was described as a "linkage with the spiritual realm." Through their human presence, words and actions, a "spiritual connection" is established between the two persons in the presence of "some other being," "the Spirit," or "God." In this role, the care provider accompanies the person on her journey to death. One provider often views her nursing work as a prelude or introduction to "the Spirit."

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> I feel my job is to be there as a presence, because they need me physically to be there. But then at some point to kind of step aside and say, 'This (the Spirit) is what's behind this.' Because they're going to need it much more than they're going to need me on their journey, and if they can latch on to that and count on that, I've given them a lot more.

Responses to Spiritual Care

Care providers reported people responding to spiritual care through their words, their facial expressions and their behaviors. Patients and families often express feelings of safety and security with their spiritual care provider. A nurse and a volunteer in HP explained:

> There's a connection, a turning point; they know they're safe. They can share the same pains over and over again, can show their emotions.

> The patient sees you as an ally which does not include any kind of guilt...When you're in the room as that unconditional entity, they're safe from other family members. The relationship produces a safety net that this patient can express their feelings; (I am) a buffer between patient and family member.

This sense of safety and security creates feelings of comfort and serenity, at times visible in the person's body language. Two nurses in HJ and a nurse in HP gave examples.

> It brings peace, a sense of serenity or comfort. Agitation decreases, the inner self is quieted.

> Once the chaplain comes in, prayers have been said, there is a calmness. There's almost a light there in the eyes that's different, that wasn't there before; and I think that's the spirit being comfortable within itself.

> People have said they feel like I'm very caring. They feel comforted, comfortable. But the verbal communication is not it; it's just the fact that there's a **connection**. I take that as acknowledgement.

The father of a young man in HP who had died of AIDS related:

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> (The) social worker didn't talk in terms of spiritual care as much as she was there as someone to lean on and provide consolation. I think that's a part of spiritual care - consoling and listening to the grief and problems and concerns...It made you feel as though there was somebody else there that cared along with you; someone who was compassionate.

Affective and behavioral reactions to music were perhaps the most striking of the reported responses. A music therapist in HJ shared her experiences.

> One 60 year old man was pretty much out of it except when I played music. I started playing and the wife started dancing. She lifted her husband and danced with him across the room. Just a beautiful moment.
>
> A woman with Alzheimer's was noncommunicative, but when I'd sing, she would transform with the music. She'd throw her head back with laughter.
>
> I thought an old woman was comatose. I went into the room with her daughter and sang campfire songs. The mother opened her eyes, got out of bed, sat in a chair and ate ice cream!

Spiritual Care Process

Scholars and practitioners have offered varied conceptualizations and paradigms of spiritual care. Many of these, although not presented as processes, imply an orderly development. Derrickson (1996) used vignettes to describe the "spiritual work" of the dying: "remembering," "reassessing," "reconciliation" and "reunion" (p.11). Smith's (1995) model of transegoic therapy used with terminally ill people is composed of four linear stages: "normalization of death," "faith in the existential self," "ego disattachment," and "self-transcendence" (p.406). Paton (1996) applies Matthew Fox's model of spiritual development to hospice spiritual care. Fox's "Sacred Circle" contains four paths of spiritual development: Via Positiva, Via Negative, Via Creativa and Via Transformativa.

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Based on the writings and philosophies of Christian Mystics, Native American Spirituality and Taoism, Buddhism and Sufism, this model emphasizes a circular and constantly changing process. Zerwekh (1993) identifies competencies of hospice nurses which fall within two phases: "spiritual caring" and "guiding in letting go" (p.27). Donley (1991) defines three components of spiritual care: suffering with the client; helping the client find meaning in suffering; and helping to remove that pain and suffering. Referring to Fowler's (1981) stages of faith, Berggren-Thomas and Griggs (1995) focus spiritual care on enhancing the person's unique spiritual journey. Grey's (1996) paradigm of spiritual care contains two axes: the psychological-spiritual axis and the being-doing axis. The provision of spiritual care involves a circular interaction between the two ends of each axis.

The goal of a phenomenological study is to arrive at a definitive description of the phenomenon (Patton, 1990). Identifying any orderly development or pattern in the occurrence of the phenomenon contributes to its definitive description. Hence, the writer asked the respondents if spiritual care involved any kind of process. No worker reported any discernible circular, cyclical or linear development with any stages or phases. In fact, many seemed to resist the idea. Grey's (1996) description of the psychospiritual axis may help explain this resistance. He indicates that, in comparison to psychological care which involves analysis, spiritual care strives for synthesis.

> It (spiritual care) does not break down or fragment; it builds up and gathers together. Spiritual care does not move downward in a process of simplification...It moves upward in a process that is syncretistic (i.e.,

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> reconciling differences in unity) and synergistic (i.e., working together) toward a source of truth (p.20-21).

Perhaps the respondents felt that identifying a spiritual care process would fragment or simplify the service, trivializing its meaning and power. Notwithstanding the workers' reports to the contrary, the writer carefully analyzed the descriptions of spiritual care to determine the presence of any process or orderly development from the time the worker meets the patient and family up to the patient's death. She found that the variety of descriptions of spiritual care involved all four of the activities on Grey's two axes: psychological care (analysis), spiritual care (synthesis), being and doing. Furthermore, an analysis of these activities revealed the ebb and flow of these four emphases during three identifiable phases of care. A diagram of this process is shown in Table 7.1.

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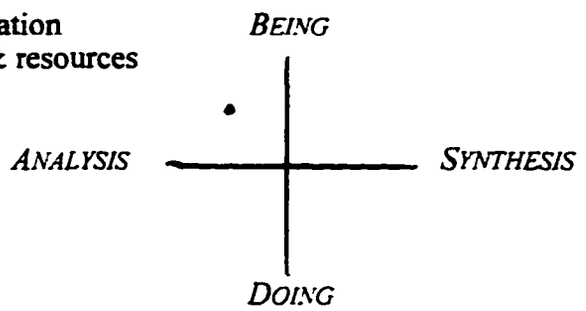
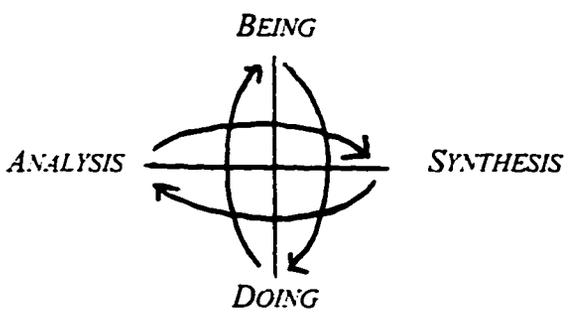
Table 7.1 – Conceptualization of Spiritual Care Process

Phase I: Analysis & Being

Non-verbal communication
Assessment of needs & resources



Phase II: Analysis/Synthesis, Being/Doing



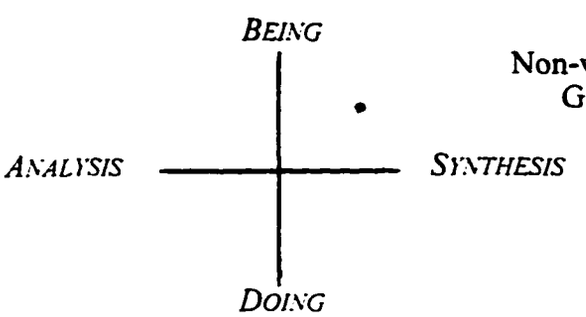
Being/Synthesis = non-verbal communication, prayer/ritual, GI. TT

Doing/Synthesis = Verbal dialogue, life review therapy, music, reading. art

Doing/Analysis = Verbal counseling about fears. insight into problems

Being/Analysis = Discern needs/fears through non-verbal communication

Phase III: Synthesis & Being



Non-verbal communication
GI, TT, Role enactment

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Phase One – Being and Analysis

When the spiritual care provider meets and forms a relationship with the patient and family, she is primarily involved in being and analysis. Exercising the principles of openness and acceptance, she engages in non-verbal communication: presence and active listening. Whether or not she is responsible for a "spiritual assessment," she engages in some level of analysis in order to achieve insights into the person's spiritual strengths and concerns. By being with, watching, listening and carefully analysing, she discerns where the person is on her spiritual journey.

Phase Two – Analysis/Synthesis, Being/Doing

Once the spiritual care relationship is established, the care provider enters the person's spiritual world or makes a "spiritual connection" with the person. This phase continues through the endstage of the illness and up to the time when the patient is approaching death. During this phase, analysis (psychological care) and synthesis (spiritual care) complement each other and are deeply interdependent. Discernment of spiritual distress facilitates an affirmation of one's belief or being which in turn may raise new concerns. "In a circular movement, analysis may lead to synthesis and synthesis to analysis" (Grey, 1996, p.21). The service provider engages in being and doing in a similar manner. Presence, listening and touch interact with dialogue, the use of ritual and/or life review. Combining body, mind and spirit, Guided Imagery and Therapeutic Touch contain elements of both being (presence, centering oneself) and doing (conducting the intervention).

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The tremendous variability in care activities reported by the workers cannot be overemphasized here. The variation occurs across patients and families. The provider may become engaged immediately in "suffering with" one patient in great spiritual distress, while another patient may reach the point of "actively dying" before any "spiritual issue" is raised. The variation also occurs within one patient over time, and the patient and family members may present divergent issues at different times. Throughout this phase, spiritual care providers are also rendering medical, nursing, psychosocial or personal care services. The vast majority prefer not to make any distinction between these services and spiritual care. Nurses in HP and HJ emphasized this point.

> Spiritual and psychosocial services compliment one another; overlap, merge. If categorize, is a disservice - you miss something.

> I believe in wholistic care...I believe in healing. You have to heal the total or strive toward healing the total existence and not just healing the body or relationships. Healing is all-encompassing and must include spiritual care.

Phase Three – Synthesis and Being

Physical symptoms associated with the "actively dying" person include irregular raspy breathing, decreased appetite, increased sleeping and changes in skin color and texture. The spiritual care providers also identified non-physical indicators of approaching death. These include reports of visions, conversations with deceased individuals and other supernatural experiences. As the patient approaches death, identifiable changes in the quality and quantity of spiritual care occur. First, there is a change in the amount of time spent with patients and families and the types of care provided. The number of visits

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increase. more time is spent with the patients and families, and more spiritual care is provided. The focus of care moves to synthesis and being. Nurses in HRC and HP and a social worker in HJ described these changes.

> As death approaches, accelerate spirituality; conversations turn to God, questions about God.

> Work enters more personal level. The people know me, trust me; tell me things no one else has heard. More frequent visits - the patient and family need reassurance. Tendency to have longer visits where you take your time with the physical assessment. It seems to be very important to have a lot of hands-on time touching, holding hands. I stay at the bedside longer, spend longer amount of time talking to the family with and without the patient.

> I move forward. The patient has greater fears, anxiety; there is an urgency to say good-bye. for family resolution. More able to talk about death and dying issues.

Time with patients and families becomes "quieter" according to two nurses in HP and a volunteer in HJ.

> Things get quieter; waiting...A lot of sitting, not much physical care.

> There's a lot less activity...More quiet supportive care provided. Reassurance; listening.

> Becomes a time of just being. Touching, laying on of hands.

Providers "say good-bye" and in other ways facilitate the dying process for themselves as well as the client according to a social worker in HJ and a minister in HRC.

> I go in and concentrate more on saying good-bye. I'll wish them a smooth journey, tell them it's OK to let go. Reassure them about an important point before they die. A lot of what I do is more for me than for them.

> Usually then the role becomes to comfort both the patient and me. I'm there to comfort and reassure and let them know that God loves them. There comes a time when people realize it's time to stop fighting and to let it take its course.

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The second major change in spiritual care involves the different foci on patients and families and, for some, a subtle shift away from the patient to the family. The primary focus is on being with the patient and family, although contact with the family often involves some very concrete activities. A social worker and a nurse in HP described these changes.

> When death is imminent or soon, the focus changes...Sometimes your focus changes from the patient to the family...Sometimes the patient is more worried about the family because they're not going to be there, depending on what their role in the family has been.
>
> Your presence becomes more important than what you say (for the patient)...For the families, what you say becomes more important.

A nurse in HP and a spiritual volunteer and spiritual staff person in HRC described their work with the family.

> I go through everything (with the family) – vital signs, heart rate - explain what they mean. I ask how they are doing and if they have supports.Towards the end, more time talking about beliefs, spirituality and less on physical aspects.
>
> The family needs more affirmation, truthfully almost, than the patient does, because the patient is weaker physically, so you're not spending as much time (with him/her). But the family still needs someone to sit with them and let them know that they're OK and that they're doing real good.
>
> I spend more time with family than patient. They appreciate my being there; caring enough to sit with, cry and comfort...Sometimes (I) read scripture and say (the) Lord's prayer aloud with the family.

Although physical care remains necessary and in some instances may even increase just before death, it becomes less significant, and spiritual care assumes dominance in the minds of the workers. Spiritual issues, spiritual events and spiritual activities are predominant in the care relationship when the patient dies.

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Cross-Agency Analysis

A strong concensus was apparent among all respondents regarding the importance of presence, openness and acceptance. These principles were clearly enunciated by a variety of staff, volunteers and the administration in all three agencies. Descriptions of spiritual care activities also were provided by varied personnel in each agency. However, there were some differences in the types of activities named by the three agencies. Nonverbal and verbal communication were reported twice as frequently as specialized techniques. creative therapies and role enactment in HRC and HP. In HJ, the latter three activities were identified almost as frequently as communication. Verbal communication involving resolution of religious/spiritual concerns and discussion of death and dying issues was the most often cited form of spiritual care activity in all three agencies. Among the creative therapies, music and ritual, prayer and reading were reported equally often. Life review was the most frequently employed specialized technique. Less traditional techniques such as GI and TT were reported only in HP and HJ. Finally, a small number in each agency reported enacting intermediary roles. Clergy called themselves an "instrument of God" or a representative of "the church community." Other staff perceived their role as a "conduit" or "midwife," facilitating the patient's transition to "the other side" or to "the spiritual realm."

A small number of workers in each agency reported patient and family responses to spiritual care with a relatively larger number of nurses reporting than other professional disciplines. These providers pointed to reported feelings of safety and security and visible

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signs of quiet, calm and decreased agitation. Those who sang or played music all reported striking, visible responses in the person's affect and/or behavior. Although no one described a discernible process in the provision of spiritual care, several respondents from each agency noted changes in the quantity and quality of spiritual care as the patient approaches death. A careful analysis of this data revealed various spiritual care activities rendered at particular times in the care relationship, defining a spiritual care process.

Conclusions

Analysis of this data across the agencies reveals some variation in the language and types of spiritual care activities utilized. Workers in HRC tended to use more traditional or theologically-based language than those in HP and HJ, and alternative healing techniques such as GI and TT were found only in HP and HJ. As discussed in the previous two chapters, these variations could be a product of the relatively greater diversity in religious, spiritual orientations among staff, patients and families in HP and HJ compared to HRC.

Beyond these differences, the descriptions of spiritual care principles and activities demonstrate a remarkable consistency. This is evident first, in the identity of the respondents. In all three agencies members of all of the professional disciplines, volunteers and the administration offered descriptions of their spiritual care. This included nurses, a social worker and an aide outside the spiritual department in HRC. Second, the dynamics of spiritual care reported by the agencies are similar. Although the types of spiritual care activities vary, workers in all of the agencies reported similar

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changes in the focus of these activities at particular times. Integrating these changes in focus within Grey's (1996) four axes of care produced a definable care process. In the first phase, the focus of care is on being (presence, acceptance, nonverbal communication) and analysis (assessment of needs and strengths). In the second phase, the care provider engages in ongoing analysis complemented in a circular fashion with synthesis. Her activities involve doing (verbal communication, creative therapies, specialized techniques) while she maintains a compassionate presence (being). In the final phase when the patient is "actively dying," the focus of care is on synthesis and being. The provider is "fully present" with the patient and family, enacting intermediary roles and otherwise accompanying the dying person on her journey.

A third area of concensus which emerged from workers' descriptions of spiritual care was the distinction made between spiritual and other types of care in each phase. In the first phase, service providers reported such distinctions. The two primary tasks in this phase are assessment of need and the establishment of a care relationship. Workers differentiated types of care based on their particular assessment (physical, psychosocial, spiritual). They connected spiritual care with establishing the client relationship: enactment of the principles (acceptance, openness) and nonverbal communication (listening). In contrast to this first phase, workers did not make any such distinction in the type of care during phase two. Instead, they saw spiritual interconnected with physical and/or psychosocial care. An aide prays aloud while she gives a back rub. A nurse responds to a patient's fears of dying while she takes vital signs. A social worker

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discusses beliefs regarding life after death while she explains advanced directives. A volunteer shares the loss of his wife while he cooks a meal. It became clear that these workers felt no need to exclusively categorize their types of care since one type involves qualities of another. Verbal communication can involve both analysis and synthesis. Physical touch can reach the person's soul as well as his body. Workers described yet a different dynamic in the third phase of care. According to Grey (1996), this is a time to "build up" and to "gather together." Physical needs decrease and spiritual encompass psychosocial needs, assuming dominance in the minds and activities of the providers.

The foregoing description of the primary tasks and foci of each phase in the spiritual care process demonstrates a progressive blurring of boundaries among the types of care. Contemporary Judaeo-Christian theological language about "the Spirit" helps illuminate this apparent erasure of boundaries. According to Johnson (1992), language of the Spirit always breaks down boundaries of neat codification or a single metaphor. No human concept can ever circumscribe it. Calling it God's movement in and through all experiences of the world, Johnson emphasizes that the Spirit embraces not only events with explicitly religious meaning, but also a wide variety of what is considered secular or plain, ordinary human life. The Spirit is the way in which everything is penetrated with connectedness and relatedness. Moltmann (1993) calls this intrinsic relationality of creation with the Spirit "mutual interpenetration," characterized by mutuality and reciprocity of love. According to Betcher (1994), when a person prepares for death, she is purged of her body and her senses. The experience of dying transcends the lines of past,

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present and future; of mind, body and soul. The dying person unites with the deceased and with all of creation.

Dying has been called a process, and phases and tasks defining the process have been identified. As originally conceptualized by Dr. Cicely Saunders, founder of hospice, dying is a spiritual journey and hospice provides care to the dying person on her journey. Contemporary writings have conceptualized spiritual care in various ways. However, its most enduring and essential feature, renamed by respondents in this study, is this accompanying of the dying person on her journey. The form or expression that this accompaniment assumes is highly variable. However, the emphases or foci of the care change in certain predictable ways from the establishment of the spiritual care relationship, through the endstage of the illness and up to the point of the patient's death. The workers' descriptions of spiritual care present a powerful affirmation of the hospice philosophy of care. Indeed, it may be in the rendering of spiritual care that providers most nearly approximate the lofty ideals and demanding requirements of this philosophy. Calling spiritual care the "heart" or "soul" of hospice, providers experience their greatest self-fulfillment when they are present with and connected to the spirit of the patient. How much greater is this feeling when they stay with the dying person, providing a "linkage" to the spiritual world, as she travels to her "true home."

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Chapter 8: Conclusions

Introduction

The purpose of this project was to describe and conceptualize the essence and structure of spiritual care in hospice. The phenomenological methodology allowed for more than one conceptualization. The participation of three hospices not only facilitated different conceptualizations; it also highlighted characteristics of spiritual care which are similar across different settings. The writer grounded this phenomenon in human experience by identifying its meanings and practices. Meanings form the context for the practice of spiritual care, manifested in its principles and practices. This section concludes with a conceptualization of the spiritual care process. The second section of this chapter discusses the implications of the study for social work and for further research.

Conceptualizing Spiritual Care

Meanings of Spiritual Care

Spiritual care providers and their patients and families bring their own meanings to the spiritual care relationship. Workers have an understanding of the terms "religion" and "spirituality"; their own religious, spiritual orientations; their motivations for engaging in this work; and their resources for coping with stress encountered on the job. Patients and families bring their religious, spiritual orientations and their particular religious, spiritual

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needs and resources to the care relationship. Workers and their clients meet under the auspices of a particular hospice with its own spiritual care program.

The Practice of Spiritual Care

Workers render spiritual and other types of care in accordance with practice principles which are consistent with the hospice philosophy of care and the social work Code of Ethics. Spiritual care activities involve multifaceted expressions through non-verbal communication, verbal dialogue, creative therapies, specialized techniques and intermediary role enactment. Patient and family responses to this care are manifested in their words, facial expressions and behaviors. Viewing these spiritual care activities within a psychospiritual matrix from the beginning of the care relationship up to the patient's death, one can discern a spiritual care process with a particular focus of attention in each of three phases.

A Conceptualization of the Spiritual Care Process

Cross-agency analysis of the meanings and practices of spiritual care reveals major differences in the level of diversity in worker and patient/family religious, spiritual orientations; and in the agencies' spiritual care program structures and cultures. These differences appear to affect the language and types of spiritual care practices utilized. However, striking similarities are evident in the use by workers, patients and families of religion/spirituality as a coping resource; and in the dynamics of the spiritual care process. As the spiritual care provider accompanies the patient and family through this

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process, boundaries merge and differences in the types of care become meaningless. Spirituality becomes ascendant, encompassing and integrating all of the dimensions of the spiritual care relationship. The spirit-to-spirit connection between worker and client, characterized by mutual interpenetration, is the essence of spiritual care and unites its constituent elements within a single conceptualization.

Implications for Social Work

The implications of this study for social work involve two issues: the role of social work in hospice and the role of social work in providing spiritual care. The first issue addresses the identity of the social worker in hospice. This discussion introduces the second issue: whether or not social work should provide spiritual care in hospice and in other work settings.

The Role of Social Work in Hospice

Quig (1989) identified the specific contributions that the social worker makes to the hospice interdisciplinary team. Millett (1983) discussed the social worker's variable roles in hospice and the inevitable role blurring with other professionals. Referring to the variable and ambiguous roles of social workers in hospice, MacDonald (1991) presents the issue as "a search for identity" (p.274). Some studies in hospice have shown that non-social workers regularly provide psychosocial services (Kulys, & Davis, 1987; Reese & Dean, 1997). Psychosocial care is a universally recognized component of hospice care, yet almost none of its professional functions are performed exclusively by social workers

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(MacDonald, 1991). This is understandable, he says, given the basic affinity between hospice and social work. McDonnel (1986) described hospice as "the embodiment of social work values, principles and practice" (p.225). Social work is oriented to a holistic, ecological perspective that views people within constantly changing social environments. Germain and Gitterman (1980) wrote,

> For social work, ecology appears to be a more useful metaphor than the older, medical disease metaphor because social work has always been committed to helping people and promoting more human environments (p.5).

This viewpoint is consistent with the hospice philosophy of care which focuses on the whole person and the patient and family as the unit of care. Given this affinity, it is not surprising to find that other hospice professionals have seemingly integrated social work values so completely that they see the practice of certain aspects of social work as part of their own function (MacDonald, 1991).

This variability in the roles of social workers and an integration of social work values across the professions was evident in the agencies participating in this study. Social workers in Hospice Roman Catholic (HRC) are responsible for "concrete," not psychosocial or spiritual services. In contrast, social workers in Hospice Protestant (HP) and Hospice Jewish (HJ) are responsible for psychosocial services and are also expected to provide spiritual care. It was common to find nurses, clergy and volunteers in all three agencies address psychosocial issues with patients and families and in team meetings.

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The question of whether or not a service should be the exclusive province of a particular profession may be meaningless in hospice. Viewing dying and death as a human experience, not a medical problem, professionals respond to the physical, social, emotional and spiritual needs of the patient and family and accompany the dying person on her journey. This orientation appears to require that social workers and other professionals perceive the "common ground" within the various services and interpenetrate each others' fields. This does not mean there is no specific role or responsiblity for the social worker (or the nurse or the clergy). How does one explicate the role? The current focus of attention in hospice on spiritual care could contribute to resolving this question.

The Role of Social Work in Spiritual Care

"The unique strength of hospice is its success in adapting a vital field of medicine to a social model of care" (MacDonald, 1991, p.280). There is evidence that hospice still struggles, after 20 years, to actualize this model of care. Some studies show that psychosocial and spiritual needs are not addressed as uniformly as medical needs (Buckingham & Lupu, 1982; Mor, 1987; Sontag, et. al, 1994). Reese & Dean (1997) point to evidence that hospice overemphasizes medical care. The organizational study by Paradis and Cummings (1986) identified an increasing isomorphism among hospice agencies over time. That is, they have become more similar to each other as well as to other health care institutions. Agency administrators in this study expressed strong concerns about hospice "becoming unbundled" and losing its wholistic orientation to

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health care. The director who visualizes a "reconceptualization of spiritual care" is actually calling for the return of hospice to its original purpose. It is noteworthy that these concerns were expressed while discussing the role of spiritual care in their agencies. All of the administrators identified this component of care as the defining element which makes hospice unique within health care. Spiritual care is critical to the maintenance of hospice's orientation to dying as a human experience, not a medical problem. These philosophical concerns exist alongside a movement within the National Hospice Organization (NHO) to define and operationalize spiritual care and in the process answer questions about who should provide the care and the various forms it must assume in a multicultural society.

In the hospice literature, physicians, nurses, clergy and social workers advocate forcefully for all service providers to render spiritual care. Ley & Corless (1988) have called spiritual care the "unfinished revolution in palliative care" (p.101). The present focus on spirituality in hospice, according to these writers, reflects a concern that care providers have been less vigorous in the pursuit of relief of spiritual pain than they have of physical or psychological pain. Although spirituality is more encompassing than religion, there has been a tendency to equate spiritual care with pastoral care and to relegate it to the clergy or pastoral counselor on the team. Ley and Corless state,

> Nothing could be more damaging to spiritual care. Spiritual needs are distinct from religious needs. All people have spiritual needs, all their own spirituality. To be effective, members of the hospice team must be able to draw from their spiritual well to satisfy the patient's needs. (p.106).

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Milton Hay, a clergy, is coordinating the effort to develop guidelines for spiritual care. He states,

> Because terminal illness may precipitate a spiritual crisis, all hospice team professionals bear some responsibility for making a spiritual assessment and directing interventions (p.25).

Several writers have offered frameworks for the provision of spiritual care which are useable by different professionals with varying religious, spiritual orientations. Paton (1996), a nurse, presents "an ecumenical, ethical framework" which incorporates many of the major spiritual philosophies. Calling upon all hospice practitioners to be "psychospiritual caregivers," Grey (1996), a clergy, presents a matrix in which all clinical practitioners can locate themselves. He emphasizes the fluid and changing nature of one's position on the matrix and the all-encompassing quality of spiritual care. Two social workers, Jones & Churchill (1994) discuss archetypal healing methods which focus on "psychospiritual care" in the relief of pain.

Should social workers in hospice provide spiritual care? "Yes." Indeed, the profession is currently providing leadership in the national movement to define and operationalize it. NHO's standards for social work (1994) are being utilized as a model to develop guidelines for this component of care. Why should social workers provide spiritual care? First, it is apparent that the trained professional already has the value base and orientation to human behavior necessary for the task. Respect for the individual, including her religious, spiritual belief system, and an ecological orientation to human behavior are consistent with the hospice philosophy of care. The possession of an appropriate value

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and philosophical base, however, is not sufficient reason in itself to require the social worker to engage in spiritual care. It is the nature of client needs in hospice which makes spiritual care an expected area of service for the social worker. Terminal illness heightens a person's awareness of and perspective on death and immortality, ultimate spiritual concerns. Studies on death and dying, the hospice literature and this study have documented the **centrality** that spiritual issues often assume in work with dying people and their families. When it is the social worker who is present with a dying person in spiritual need, relegating this service to a clergy represents a disservice to the patient. It also repudiates the hospice revolution against modern medicine with its carving up of the patient into descrete parts, each allocated to a different profession. Hence, the question is not whether or not the social worker should provide spiritual care but what training is necessary to adequately equip her for the task.

The spiritual care providers in this study helped to identify the knowledge and skills necessary for social workers (and other non-clergy) to render spiritual care. First, an awareness of one's personal religious, spiritual belief system is essential. This goes beyond a particular religious affiliation to include an understanding of her spiritual dimension. Second, spiritual care providers need to learn the indicators of religious, spiritual needs and resources among their patients and families. Finally, the service provider should be equipped with the appropriate language and skills to respond to religious, spritual needs. The workers also identified several important guidelines for this education. First, spiritual care providers must be "spiritually competent." Although

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practitioners should be familiar with the religions typically practiced by their particular clients, this does not require mastery of the major theological systems. Rather, religion/spirituality should be an integral part of social work training to be "culturally competent" practitioners. Second, a social worker may wish to learn specific healing techniques, but these are not required. Rather, she should be comfortable with the language and able to incorporate spiritual care into her professional values and psychosocial counseling skills. Finally, the social worker (and other non-clergy) should know when to refer a client to "the expert," and this expert should be a **spiritual**, not only a religious resource. Derrickson (1996) makes a distinction between "spiritual support" and "spiritual intervention" which provides a guideline for making a referral. All service providers should render spiritual support:

> Spiritual support is simply to recognize spiritual work (in the patient) when it is being done, to listen to and respect the other's individual expression of their spirituality, and to be willing to share our own spiritual pilgrimage when appropriate. Often all that is required is to listen to the other with empathy and respect.

A trained clergy or pastoral care counselor is qualified to make a spiritual intervention.

> A spiritual intervention is an attempt to assist a patient or family member in wrestling with a spiritual question or in dealing with spiritual distress or a spiritual crisis. (p.13).

The analogy for the social worker is the difference between "psychosocial support" and "psychosocial intervention." Non-social workers in hospice provide psychosocial support. The Master's level social worker is trained to provide psychosocial intervention when the client presents significant individual or family psychosocial distress. This distinction

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between support and intervention in psychosocial and spiritual care explicates the roles of the various professionals who interpenetrate one another's fields of practice. While each professional provides ongoing psychosocial and spiritual support, they call upon the expertise of the other when severe psychosocial or spiritual distress is evident.

The social workers and other care providers in this study conveyed one final message regarding the ability of a non-clergy to provide spiritual care. It is not only possible to render this service without imposing one's belief system on the client. The care is most effective when the provider is aware of and makes affirmative use of her "grounding philosophy" in the care relationship. This interaction between the worker's belief system and her professional practice facilitates the spirit-to-spirit connection between worker and client which is the essence of spiritual care.

Hospice represents a field where religious, spiritual issues are ever present and require the intervention by non-clergy service providers including social workers. Should the social worker attend to clients' religious, spiritual issues in other practice settings? "Yes." These issues may be more dominant in hospice than in other fields. It is also clear that agencies define the context within which these issues may arise and the parameters for addressing the concerns. However, religion and spirituality are a part of all clients' lives and the spiritual dimension of a person can be an important component in defining her world view. Ignoring this area of "indigenous knowledge" renders the social worker less effective in her collaborative search for meaning with the client. If spirituality is

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important to the client, the profession has no choice. It is obligated to include religion/spirituality in its education.

The social work literature indicates the need for several things in order to integrate religion/spirituality within education. These include: a systematized body of knowledge and skills including a conceptual scheme for assessing client religious, spiritual needs; and a concensus around terminology that accounts for a pluralistic profession and society. Much of this information already exists among the many, varied social work scholars, educators and practitioners engaged in this effort. A variety of practice models have been developed. Educators have presented ways to incorporate the subject into existing courses in human behavior, practice, policy and administration. Courses on religion, spirituality and social work are being offered and include techniques for assessing one's personal religious/spiritual orientation as well as that of the client. The work to develop empirically grounded conceptual frameworks needs to continue, and this information should be organized and made available to social work educators. The North American Association of Christians in Social Work (NACSW) was incorporated in 1954, publishes Social Work and Christianity: An International Journal and sponsors an annual conference. The Society for Spirituality and Social Work was established in 1990, publishes a newsletter and sponsors an annual conference. Members contribute frequently to the journal Social Thought: Religion in the Social Sciences and increasingly to mainstream social work journals. Perhaps the profession should look toward these educators and practitioners for guidance.

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Peoples' attitudes toward the subject should be addressed also. Religion stimulates thoughts in many of a coercive or oppressive ideological system. Concerns remain about how one can incorporate the subject into practice while respecting client self-determination. Clark (1996) voices the suspicion, held by some, that the effort to reintegrate the topic within the profession is actually a disguised move to "place religion in an ascendant position in social work education, practice and research" (p.15). This would, according to Clark, repudiate the person-in-environment orientation and return the profession to a moral focus on the individual as the problem. In the process, social work would risk losing its professional status. This study indicates that the reintegration of religion and spirituality within social work education falls well within the profession's existing ethics and ecological orientation to human behavior. It also identifies some boundaries for the content of this education. Finally, it demonstrates how the worker can make use of her belief system in professional practice while affirming the client's world view.

One might develop a level of comfort with religion, elements of which can be viewed externally. The abstruse, transcendent qualities of spirituality, on the other hand, seem to defy description and can create feelings of distress in the uneducated practitioner who is confronted with spiritual concerns. Studies such as this one help to demystify the subject by grounding its practice in human terms. The integration of this subject into social work education will not only address informational deficits; it will also make the topic more "user friendly."

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Implications for Further Research

This study produced several preliminary findings which should be examined further. A single conceptualization of spiritual care emerged among three agencies that serve predominantly either Roman Catholic, Protestant or Jewish clients. The outcome might have been different had the agency selection criterion been clientele who varied from orthodox/fundamental to reform/liberal in their religious orientations. Participation by a greater proportion of persons of color could have enhanced the diversity of religious, spiritual belief systems and approaches to spiritual care. The relatively small number of male respondents does not appear to play any significant role in the study's outcomes. The contributions to this study by social workers reflect their varied roles in the three hospices. In HP and HJ where social workers are expected to render spiritual care, they contributed more data than in HRC where they provide primarily "concrete" services. This study's example of social workers making affirmative use of their belief system in practice is very useful to the profession. A study focused on hospice social workers who provide spiritual care could enhance understanding of this dynamic.

Respondents pointed out the powerful relationship between religious, spiritual resources, including hospice spiritual care, and the quality of a patient's death. The definition of terms and identification of specific spiritual activities provided by this study make feasible an investigation of the outcomes of spiritual care. This raises the issue of service evaluation. The challenge is to develop sensitive, ethical ways, grounded in human terms, to evaluate this aspect of human service. Patton (1990) discusses the need for special

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sensitivity to and respect for differences when conducting studies in cross-cultural settings. "To ask is to seek entry into another's world. Therefore, ask respectfully and with sincerity" (p.359). These simple words assume a profound meaning when asking questions about spiritual care. The study of this subject takes the evaluator into intensely private areas of people's lives which define their world view and provide meaning in their lives. The workers' resistance in this study to identifying a spiritual care process could be an indication of people's reluctance to engage in any effort which, they believe, fragments spirituality, diminishing its meaning and power.

The challenge of conducting an evaluation of spiritual care is magnified in hospice where the client is dying. Spiritual care providers listen to people in pain who are broken, full of fear, marginalized, **vulnerable**. Care providers let themselves be touched and their hearts be opened. Not only are they competent, but they are also compassionate. At times they experience their own deepest fears. They feel empty-handed, powerless; they become vulnerable. Sheila Cassidy (1992), a physician and social worker, believes that the world is not divided into the sick and those who care for them, but that all people are wounded; hence, the metaphor of the wounded healer for the hospice spiritual care provider.

The evaluator of spiritual care in hospice should also appreciate what hospice represents in health care. Cassidy calls hospice "the prophet" in medical care - people who are called both to listen and to speak out for the oppressed. What is hospice saying?

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> We listen to the cries of the people and try to speak out for them. We relate that they want to be treated as normal, responsible persons...They want to retain their dignity as individuals and keep some control over their lives. They want us to be honest with them and humble. More than anything, they want us to combine our competence with compassion and, when our hands are empty, to stay our ground and share the frightening darkness with them (p.21).

Finally, the service evaluator needs to be sensitive to shifts in her own feelings and attitudes (Patton, 1990). The sensitive person who evaluates spiritual care in hospice more than likely **will be touched** as this writer has been touched. The experience may lay open new thoughts, feelings and beliefs as well as knowledge. The ability to make affirmative use of this personal and professional experience is, perhaps, the essence of what it means to integrate religion and spirituality within social work.

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APPENDIX A

LETTER TO STAFF AND VOLUNTEER INTERVIEWEES

Dear

I am delighted that you have agreed to talk to me about providing spiritual care to your patients and families. As you know, there is little concensus among hospice agencies about what spiritual care is, who should provide it and how. I am studying how spiritual care is provided in hospice by interviewing staff and volunteers and a few patients and their families.

The purpose of my study is to describe the essence of spiritual care as it is provided by staff and volunteers and experienced by patients and families. I have prepared some questions for our interview relating to:

How you came to work with terminally ill people,
The religious, spiritual needs and resources of your patients and families, and
What you do when you provide spiritual care.

We will not be limited to these questions since I want to hear whatever you think is relevant and important. You are the expert, I am the student learning from you. With your permission, I will record our interview in addition to taking notes. All persons' names and the agency will remain confidential. The results of this study will become part of my doctoral dissertation at the Hunter College School of Social Work. I will also share the findings in summary form with the agency.

When we meet, I will answer your questions about the study and will ask you to sign a consent form before the interview begins. I look forward to talking to you and learning about the wonderful services that you provide.

Sincerely yours,

Diana S. Batten, ACSW, LCSW

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APPENDIX B

INTERVIEW WITH STAFF AND VOLUNTEERS

Opening Statement:

As I said in my letter to you, I am studying how spiritual care is provided in hospice agencies. I am beginning with staff and volunteers who are experienced in providing this service - people like you. I want to describe the essence of spiritual care - how it looks and feels - using your own words since you are the expert. I have developed several questions but I want to hear what you think is relevant and important, so don't feel limited by these questions.

First, I would like to get your written consent to participate in this interview (review consent form). I would like to record our interview with your permission so that I am not too tied up taking notes. The results of this study will become part of my doctoral dissertation at the Hunter College School of Social Work. I will also share a summary report with the agency since it is interested in improving its spiritual care program. Do you have any questions or concerns?

[We will begin with your work here.]

1. What is your job title and your responsibilities?
   -number of cases, frequency of visits

2. How did you come to work with people who are dying?
   -how came to this agency

3. Do you see any connection between your work with dying people and your own religious or spiritual background/ beliefs?
   -source(s) of beliefs/values
   -beliefs/values about dying, death, evil in world
   -what mean by "spiritual" & "religious"

[Now I would like to learn about your patients and their families.]

4. What are some of the religious/spiritual needs of your patients and families?
   -how expressed
   -how often they arise
   -religious: sacraments, church attendance, Bible reading

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-spiritual: lack of personal meaning system; no inner peace; lack of love/relatedness; lack of love, hope, trust; shame/inadequacy in the face of death; unfinished business
-family member: anger, remorse, grief

5.What are some of the religious/spiritual strengths or resources you have seen your patients/families call upon and use?
-religious practices, beliefs, community
-spiritual practices, beliefs, community
-inner resources/peace, sense of connectedness
-difference they make

[Now I have several questions about providing spiritual care to your patients and their family members. In answering these questions, you may want to remember times when you have provided this care.]

6.How do you respond to religious/spiritual needs of patients and families; how do you provide spiritual care?
-actions/behaviors; words; non-verbal language; thoughts; feelings
-manifestations/expressions of spiritual care: (sacraments, Bible reading, prayer, meditation, sharing spiritual thoughts/beliefs, guided imagery)
-how patients/families respond
-impact on care relationship

7.Do you see the patient's & family's needs change as death draws near?
-do anything differently
-any process, stages or cycle in work with patient/family; as death approaches

8.Have your experiences with dying people affected your own religious, spiritual beliefs about death? life?
-coping with repeated deaths and loss of relationships
-toughest and best parts of job

[One final question.]

9.How do you feel about the agency's spiritual care program? Would you make any changes?

That completes my questions. Are there any additional comments you would like to make or any questions you would like to ask? Thank you for talking to me and sharing your valuable knowledge and experiences.

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APPENDIX C

INFORMED CONSENT FORM - STAFF AND VOLUNTEERS

Please Read the Following Carefully

Participation in this study is voluntary. There will be no penalty or loss should you decide not to participate. Withdrawl from the study at any time, even after you begin, will not affect your employment in any way. If it makes you uncomfortable for any reason, you should stop.

Your identity as a participant in this research will remain confidential with regard to any publications and oral presentation of the study results. The record of your participation will be maintained and kept confidential by the researcher.

If in the course of the study we find that a follow-up contact is needed, we will let you know.

As a participant, you will be asked to do the following:

> Participate in a face-to-face interview with Diana Batten, the researcher. The interview will be conducted at the agency during regular working hours and will last up to 90 minutes. You will be asked to answer questions about the provision of spiritual care services to your patients and families.

The following benefits are expected to result from the study:

> The study is expected to generate a clearer understanding of spiritual care, leading to improved services for the agency's patients and families.

I volunteer to participate in the research study. I understand what I will be asked to do as a participant; that my identity as a participant will remain confidential; and that I may withdraw my participation at any time. I have had the opportunity to ask questions about the study and my participation. All of my questions were answered to my satisfaction.

_____ _____

Signature Date

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APPENDIX D

INTERVIEW WITH PATIENTS AND FAMILIES

1. Prefatory comments-succinct statement of purpose

2. Could you tell me about your current life?
   -family, friends, activities, demographic information

3. Could you tell me about your illness?
   -diagnosis, history, current status

4. Could you tell me about your past life?
   -family, work, hobbies, travel, friends

   What were some "critical events" in your life? How do you remember coping with them?

   (This will include questions to elicit past religious/ spiritual affiliation/involvement).

5. How has your life changed as a result of your illness?
   -adaptation or coping
   -who or what helpful or not helpful

   (These questions are asked if information is not previously provided).

6. How would you describe your present religious or spiritual affiliation/involvement?
   -beliefs, values, practices

7. Illness and religion/spirituality (use person's terminology)

   Have you found religion/spirituality helpful or not helpful in coping with your illness?
   -resources, needs
   -changes during course of illness
   -attitude towards death

8. Spiritual care

   Have you received "spiritual care" from anyone during your illness? Who? Anyone from hospice?

   How have you experienced this care?
   -positive, negative, indifferent

   What influence, if any, has spiritual care had on your feelings; values; beliefs; attitude about life and death?

9. Are there any other comments you wish to share?

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APPENDIX E

INFORMED CONSENT FORM - PATIENTS

Please Read the Following Carefully

Participation in this study is voluntary. There will be no penalty or loss should you decide not to participate. Withdrawl from the study at any time, even after you begin, will not affect the services you receive from hospice in any way.

Your identity as a participant in this research will remain confidential with regard to any publications and oral presentation of the study results. The record of your participation will be maintained and kept confidential by the researcher. If in the course of the study we find that a follow-up contact is needed, we will let you know.

As a participant, you will be asked to do the following:

Participate in a face-to-face interview with Diana Batten, the researcher. The interview will take place in your home at a time that is convenient for you. You will be asked questions about the provision of spiritual care by hospice care providers.

The following risks may be invovled as a result of your participation:

You might experience some emotional discomfort as a result of your interview. If you feel that you have experienced any problems, you should contact your hospice care provider.
Name _____ Phone _____

The following benefits are expected from the study:

The study is expected to generate a clearer understanding of spiritual care, leading to improved services for hospice patients and families.

I volunteer to participate in the research study. I understand what I will be asked to do as a participant; that my identity as a participant will remain confidential; and that I may withdraw my participation at any time. I have had the opportunity to ask questions about the study and my participation. All of my questions were answered to my satisfaction.

_____ _____
Signature Date

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APPENDIX F

INTERVIEW WITH AGENCY ADMINISTRATOR

Opening Statement:

As you know, I am studying how spiritual care is provided in hospice agencies. I am interviewing staff and volunteers who provide spiritual care and are able to describe their work. I will also interview a few patients and families recommended by staff to obtain their experiences with spiritual care.

I would like to discuss spiritual care as an agency program with you. I will tape the interview with your permission. All persons' names and the agency will remain confidential. The results of this study will become part of my doctoral dissertation at the Hunter College School of Social Work. I will also share a summary report with the agency since it is interested in improving its spiritual care program. Do you have any questions or concerns?

[We will begin with your employment here. Confirm job title, years of service, responsibilities.]

[Now I'd like to ask several questions about the agency's spiritual care program.]

1. What is the history, if you know, of spiritual care in this agency?
   - -how recently incorporated
   - -who/how incorporated

2. Could you describe the current spiritual care program?
   - -trained staff (clergy and non-clergy)
   - -training of other staff
   - -who provides spiritual care; how understood/perceived
   - -who/how spiritual needs/concerns of patients/families assessed
   - -how/when spiritual care incorporated into care plan
   - -how spiritual care documented in records
   - -how spiritual care evaluated, if done

3. What is your role, if any, in the agency's spiritual care program?

4. How would you evaluate the spiritual care program?
   - -how well-defined, understood generally
   - -how broadly provided by different staff/volunteers
   - -comfort level of staff/volunteers with spiritual care
   - -how well reinforces agency values
   - -what changes would like to see
   - -other strengths/needs

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[Now I'd like to ask a few questions about the agency's patients and families.]

5. What is the breakdown, to your best knowledge, of the religious backgrounds of your patients and families?
   -% Protestant, Roman Catholic Jewish
   -% other

6. To what do you attribute this breakdown?
   -geographic area served
   -history of agency (sectarian auspices, founder)
   -other

7. How, if at all, do you think the agency's spiritual care is influenced by its history, culture and/or the religious backgrounds of its clientele?
   -agency history/culture: artifacts (symbols, publications); behaviors; underlying values; religious backgrounds of staff
   -religious backgrounds (Protestant, Roman Catholic, Jewish, other)

8. Do you see any other factor(s) that has influenced how spiritual care is provided by the agency?

[One final question.]

9. What would you like to get out of this study for yourself and for the agency?
   -feedback from researcher
   -stronger spiritual care program
   -validation of perceived needs for spiritual care program

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APPENDIX G

SPIRITUAL ASSESSMENT - HOSPICE ROMAN CATHOLIC

Patient Name_____
Hospice No. _____

Religion of Patient_____ Family, if different_____

Church Affiliation_____ _____

Name of Clergy_____ _____

Address_____ _____
_____ _____

Telephone_____ _____

Types of Spiritual Care Desired

Primary Community Clergy _____ Primary Hospice _____
Joint, Community-Hospice _____ None Desired Now ____

Spiritual Concerns, i.e.

Anger, Guilt, Abandonment, Fear, Despair, Betrayal, etc.

Spoken _____

_____

_____

_____

Unspoken _____

_____

_____

_____

Pastoral Care Plan _____

_____

_____

_____ _____
Spiritual Assessor Date

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Religious Practices - Spiritual Concerns

Church Membership _____

Expression of Spirituality _____

_____

Philosophy of Life _____

_____

Important Events _____

_____

Enjoyments _____

_____

Past critical events _____

Support Systems _____

_____

Feelings about God_____

_____

Feelings about self _____

Belief in life after life _____

Faith and hope _____

_____

Existential meaningfulness _____

_____

Things uncompleted _____

_____

Epilogue _____

_____

_____ _____

Spiritual Assessor Date

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APPENDIX H

SPIRITUAL ASSESSMENT - HOSPICE PROTESTANT

1. Beliefs/spiritual practices important to patient/family

2. What type of spiritual/religious support does patient/ family desire from hospice?

3. What role will religious members have in patient's care?

4. Specific religious information, when applicable

   a. Religion_____

   b. Name of church, synagogue, temple_____

   c. Pastor's/Rabbi's Name_____

   d. Telephone_____

   e. Does patient/family wish hospice to contact clergy?

   ___ Yes ___ No ___ Other

5. Comments/Plans

6. Information Source:

Date_____ Signature of Assessor_____
Signature and Title

Patient's Name
HMR#:

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APPENDIX I

SPIRITUAL ASSESSMENT - HOSPICE JEWISH

(Completed by Social Worker)

Initial Psycho-Social Assessment PATIENT NAME AND M.R. #

LIVING ARRANGEMENTS (COMPOSITION OF HOUSEHOLD, DESCRIPTION OF HOME OR APT) _____

ETHNIC BACKGROUND AND LANGUAGE: _____

OCCUPATIONAL/EDUCATIONAL EXPERIENCE: _____

HOBBIES/INTERESTS: _____

FINANCIAL ASSESSMENT

PRIMARY SOURCE OF INCOME: _____

BENEFITS RECEIVED (i.e. SSI, SSD, PENSION): _____

☐ NEED FOR COMMUNITY RESOURCES/REFERRAL (TO): _____

☐ NEED FOR FURTHER FINANCIAL EVALUATION/HOSPICE ASSISTANCE (SEE FINANCIAL SCREEN):

☐ WILL EXECUTED: IF NOT, PLAN FOR COMPLETION: _____

☐ HEALTH CARE PROXY COMPLETED OR DISCUSSED. ADD'L INFO: _____

SIGNIFICANT (HEALTH) HISTORY OF PCG AND FAMILY: _____

PAST LOSSES: _____

SPIRITUAL ASSESSMENT (TO INCLUDE PATIENT/FAMILY SPIRITUAL BELIEFS THE IMPORTANCE OR MEANING OF THESE BELIEFS, IDENTIFICATION OF PRESENT/PAST/RELIGIOUS AFFILIATION, RITUALS PRACTICED OR BELIEFS RELATED TO ILLNESS, SUFFERING, RECONCILIATION, DEATH, LIFE AFTER DEATH):

LOCAL CHURCH/SYNAGOGUE (NAME, ADDRESS, CLERGY CONTACT):

☐ DESIRE FOR HOSPICE CHAPLAIN TO CONTACT LOCAL CLERGY

☐ DESIRE FOR HOSPICE CHAPLAIN CONTACT

FUNERAL PLANNING (SEE INFO. RECORD FOR PLANS):

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IMPRESSIONS OF PATIENT (TO INCLUDE AFFECT, MENTAL STATUS, PREMORBID PERSONALITY, COGNITIVE AWARENESS OF DIAGNOSIS/PROGNOSIS, LEVEL OF EMOTIONAL INTEGRATION, COPING/DEFENSE MECHANISMS, COMMUNICATION STYLE, AND HISTORY OF RELATIONSHIP WITH PCG, ROLE OF PATIENT IN FAMILY SYSTEM):

IMPRESSIONS OF PCG/FAMILY SYSTEM (TO INCLUDE IDENTIFICATION OF PCG AND AVAILABLE SUPPORT SYSTEMS, STRUCTURE AND FUNCTIONING OF FAMILY SYSTEM, PATTERNS OF COMMUNICATION, COPING/DEFENSE MECHANISMS):

GOAL AND PLAN OF INTERVENTION:

SIGNATURE AND TITLE **DATE**

REPRESENTATION OF FAMILY SYSTEM/GENOGRAM

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APPENDIX J

SPIRITUAL ASSESSMENT - HOSPICE JEWISH

(Completed by Pastoral Care Coordinator)

SPIRITUAL ASSESSMENT

Religion: _____ *Church/Synagogue:* _____

Religion of Primary Care Giver, if different: _____ *Address:* _____

Clergy Name: _____ *Phone: ( )* _____

Spirituality, Philosophy of Life and Death: (Do you see yourself as a religious person? How do you practice religion? Has this changed since your illness?)

Patient: _____

Primary Care Giver: _____

Spiritual Concerns/Needs (Specify patient, primary care giver (PCG), or both):

_____*Fear of death*
_____*Hopelessness*
_____*Unresolved grief*
_____*Loss of meaning of life*
_____*Unanswered prayer*
_____*Unresolved past (guilt)*
_____*Religious conflicts with Palliative Care*
_____*Estranged from church/Synagogue*
_____*Resentments/anger*
_____*Confusion/doubts re: beliefs*
_____*Why me?*
_____*Low self-esteem*
_____*Inability to carry out religious duties*
_____*No apparent concerns*

Religious Services Desired (Specify patient, primary care giver (PCG), or both):

Comments:

Referral: *[]Hospice Chaplain to call* *[]Patient's own Clergy to follow* *[]Hospice Chaplain to call patient's Clergy*

Completed by: _____ *Date:* _____
Signature and Title

SPIRTASS.DOC
8/4-7/94

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