Title
Hospice and the Spiritual Experience of Dying

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Publication Date
1999-04-01

Hospice and the Spiritual Experience of Dying

by

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B.S. (The University of Michigan) 1996

A thesis submitted in partial satisfaction of the

requirement for the degree of

Masters of Science
in

Health and Medical Sciences

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, BERKELEY

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Spring 1999

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5/18/99
Date

University of California, Berkeley

Spring 1999

Dedication

This work is dedicated to my dad, Blake Wales Hendee Smith, who died in August of 1998. In the last year of his life, I watched my dad undergo a profound spiritual transformation. He become more open and kind. He became more accepting of the love of others. He started having conversations with his deceased father. Working on this topic has allowed me to keep in touch with what was really important to me this past year.

Acknowledgments

I would like to thank my thesis committee members for their teaching, support, and encouragement. Jeff Burack has watched my thesis topic evolve from gun violence to disability determination for the homeless, to the effects of environmental tobacco smoke, and finally to spirituality in hospice patients. He has been encouraging and insightful at every step. I am especially grateful to Jeff for starting his study early so that I could use the data for my thesis.

I would like to thank the chair of my committee, Patricia Morgan. After meeting Patricia relatively late in these three years of study, in that short time, she has profoundly influenced my attitude toward social science research. Without her qualitative research acumen and persistent drive toward quality I would have been lost. Tom Boyce has been very helpful in guiding the overall vision of the project, particularly with regard to the description of spirituality and the spiritual experience of dying. Guy Micco has been a tremendous resource. This semester I had the pleasure of working for Guy as a Graduate Student Instructor in an interdisciplinary course titled, "Death: Yesterday and Today." This course provided a wealth of information as well as stimulating discussions relevant to my thesis. Additionally, although Guy held strongly to his personal beliefs on many issues, he never presented issues from a single point of view, but always from multiple perspectives.

I would also like to thank several individuals not on my thesis committee. Steve McPhee has been a spiritual advisor to me. He strongly believes that in order to relate to patients about their spiritual experiences, a person must be familiar with his or her own spirituality. He encouraged me to use this experience as an opportunity to grow

spiritually. Talking with dying patients and deciding how to describe spirituality were experiences that forced me to confront basic issues about my own beliefs, values, relationships, and spirituality. Robert Ratner was deeply interested in this topic. Robert provided a critical, analytical perspective that was invaluable to me. He was willing to talk with me in depth about my thesis, whether the issue was a new description of spirituality or the outline of my thesis. Heather Ashare provided love, support and a listening ear these many months.

Finally, I would like to thank the subjects of this study for revealing their thoughts and feelings, for opening up their hearts, and for sharing their experiences in dying with me.

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Chapter One: Introduction

A 1997 Gallup survey on spirituality and the dying process found that 70 percent of people prefer to die at home (Gallup 1997). In this century, however, death has moved from the home to the hospital. Between 1949 and 1980 the percentage of deaths in hospitals jumped from 39.5 percent to 60.5 percent (Field and Cassel 1997). In the mid 1980's, Medicare began both to cover hospice care and to encourage hospitals to reduce their acute-care expenditures. A small but significant shift took place as more people died at home. In 1992, 57 percent of deaths occurred in hospitals, 17 percent in nursing homes, 20 percent in residences, and 6 percent elsewhere (Field and Cassel 1997).

Hospice is an institution that provides end-of-life care for terminally ill patients. In the United States most people receiving hospice care die at home (Connor 1998). Hospice is a palliative care organization. Care begins for patients with a terminal prognosis when they have ceased to seek curative care and pursue palliative care exclusively. In the United States, somewhere between 11 and 17 percent of people who die are in hospice care (Field and Cassel 1997). In a 1996 Gallup poll, 70 percent of respondents indicated that they would seek hospice care; however, 62 percent also indicated that they would seek curative care (Field and Cassel 1997). Because hospice requires people to forgo life-prolonging treatment, these percentages reveal a contradiction between expectations about hospice care and what hospice actually provides.

Hospice was created to address the particular needs of dying patients (Lattanzi-Licht and Connor 1995). Concerns of dying patients, while not unique, represent a shifting of priorities, as certain needs become exaggerated and others diminish in importance (Koenig quoted in Lattanzi-Licht and Connor 1995):

> To be in pain, dependent ... in a state of isolation from one's family, to lose authority to influence the course of one's life – these exigencies can be more threatening than death.

The 1997 Gallup poll found that the most prevalent concerns among people when they think about death include: the possibility of being vegetable-like for some period of time (73 percent), not having the chance to say goodbye to someone (73 percent), the possibility of great physical pain before you die (67 percent), how your family or loved ones will be cared for (65 percent), and thinking that your death will be the cause of inconvenience and stress for those who love you (64 percent). Concerns ranged from physical to psychological to social to spiritual.

This paper will focus on the spiritual aspects of dying. Dying often raises spiritual issues, and may accelerate a person's need to address spiritual concerns (Byock 1997). Although a great deal of theory has been proposed on the spiritual experience of dying, comparatively little research has been done. Spirituality in hospice has been labeled the "ignored dimension" of hospice research (McGrath 1997). Research that has been done has been primarily quantitative (Millison 1995; Babler 1997). Using qualitative methods, this study provided the unique opportunity of allowing theory to emerge from the lived experience of the dying. A total of nine patients in hospice were interviewed. For some patients, data from multiple interviews were used to tracked changes over time.

This paper will also examine the role of hospice in the spiritual experience of dying. This relationship will be studied from the perspective of hospice patients, their caregivers, and physicians. Hospice claims to provide spiritual care for dying patients (Connor 1998). According to some, spiritual care is as important or a more important aspect of hospice care than physical care (Ackerman 1997; Perrino 1999). What exactly this spiritual care consists of will be analyzed, both in the literature and from these multiple perspectives.

As a future physician, I am particularly interested in the physician's role in the transition of a patient to hospice care and the dying experience. What role or roles are there for physicians in the care of dying patients? Can physicians provide spiritual care? Ought physicians provide spiritual care?

I will begin by describing spirituality and differentiating it from religion. Models of the spiritual experience of dying will be discussed as described in the literature. Hospice will then be described including both historical and critical perspectives. Spiritual care models presented in the literature will be organized into three categories. Qualitative research methods and a background of the study population are described. Findings are presented in two sections. First, I present three themes that emerged from these patients' spiritual experience of dying: (1) finding meaning or purpose in dying, (2) what happens after death, and (3) resolving relationships, forgiveness and reconciliation. Second, I examine hospice's role in the spiritual experience of dying from the perspectives of the patients, a caregiver, and three physicians. The paper concludes with a discussion of how these findings compare to the literature. Included in this discussion are implications for the roles of hospice and physicians in the spiritual experience of dying.

Chapter Two: Literature Review

Spirituality

What is Spirituality?

Before beginning the interviews, I felt I needed to be clear about what I was investigating. I found that spirituality has been defined in several ways (Welch 1985; Lunn 1993; Klass 1995; Connor 1998; Weiss 1998). I was not comfortable defining spirituality, but I did feel that I could list its characteristics. For an individual, spirituality may be one or any combination of these characteristics. Spirituality can be described variously as:

- the experience of a purpose or meaning in existence;
- relationships to self, others, and a higher power;
- the belief in ultimate truths, values, or concerns; and/or
- the experience of awe or transcendence.

Notice that spirituality is described as experiential, as relational, and as a set of beliefs. Spirituality has also been characterized as the experience of awe or transcendence. Experiences of awe and transcendence reveal inter-connections between ourselves and others or between ourselves and a higher power. These experiences confront us with the mystery and profundity of our spiritual nature.

A religion may provide a framework of experiences, relationships, and beliefs; however, spirituality need not arise from a particular religion. In distinguishing spirituality from religion, Lunn, a minister, wrote:

> The spiritual dimension is the deepest and is concerned with ultimate concerns, our search for meaning and values. It is often experienced in terms of relationships, possibly with God but almost certainly with others and self. Religion on the other hand is the corporate, organized and outward expression of belief systems and an attempt to describe and express faith, ordinarily in community (Lunn 1993).

Spirituality can be described as personal, religion as organized and corporate.

I believe spirituality is a fundamental component of all sentient beings, whether they identify themselves as religious or not. Maslow, a humanistic psychologist, wrote:

> The human being needs a framework of values, a philosophy of life, a religion or religion-surrogate to live by and understand by, in about the same sense that he needs sunlight, calcium, or love ... We need a validated, usable system of human values that we can believe in and devote ourselves to (be willing to die for) (Maslow 1968).

Just as everyone's psychology and biology is unique, so is everyone's spirituality. Every person develops his or her own set of beliefs and values, ways of knowing and relating, and experience of God, ultimate truths or values. Life confronts all people with unique challenges and privileges, losses and successes, hopes and fears, so that just as each person's life is his or her own, so is spirituality individuated. Thus, spirituality is both common to all people and unique for each individual.

Carson described spirituality as a unifying concept through which our psychosocial and biological selves relate (Carson 1989). I do not believe the relationship between these different aspects of our being is this clear. For the purposes of this research, I will state simply that relationships exist among the biological, social, and psychological aspects of our being. This thesis will attempt to elucidate some of these relationships more clearly. Additionally, one can see how this definition of spirituality is inclusive of certain existential and philosophical concerns. This is not to say that these concerns are equivalent, or that they are all in fact spiritual concerns. Rather, it highlights the overlap between these areas of human experience and the broad scope of human spirituality.

Spirituality and Dying

New experiences often provoke anxiety and fear, and thus they provide the opportunity for re-examination, growth, and development. Experiences of loss, change, and impermanence are reminders of our own unavoidable death. Death has been described as the "motivator of spirituality (Klass 1995)." The process of dying may raise one's awareness of the spiritual nature of one's being. Welch, a hospice director, wrote, "An awareness of terminal illness seems to precipitate crises in many areas of one's life and to force one to view differently all one's connections with the world. Patients seek answers to questions that may be deeply sensed yet unarticulated (Welch 1985)."

The Spiritual Experience of Dying: Four Models

Efforts to characterize more specifically the effect of dying on individual's spirituality are multiple. Models proposed include those based on spiritual growth, development, pain, needs, and work (Kubler-Ross 1969; Fowler 1981; Welch 1985; Kearney 1996; Byock 1997; Connor 1998; Dass and Vaughan 1998; Poulson 1998). Although important differences among these models exist, the similarities outweigh the differences. For example, the use of terms such as spiritual issues, needs, concerns, and work, although distinct in meaning, are really variations of degree on a continuum. Need, for example, describes something without which a person suffers. Concern, on the other hand, describes a state of interest and anxiety, but does not denote suffering if not addressed (Costello 1997). An issue that is a spiritual concern for one person may be a spiritual need for another. By seeking out similarities, I have organized these models into four categories: spiritual pain models, needs-concerns models, growth models, and developmental models.

In the first category of models, spiritual suffering is as much a reality as physical suffering. It is not unusual for dying patients to experience spiritual distress when confronted with death. Cassel, in a landmark paper, described multiple forms of suffering as integral components of personhood (Cassel 1982). He took to task the traditional Western view that all suffering arises from physical pain. Kearney described "soul pain" as "the experience of an individual who has become disconnected and alienated from himself (Kearney 1996)." Soul pain, Kearney argued, often manifests as physical pain, and is mistreated. Poulson described this physical expression of spiritual suffering as a "spiritual dysphoria (Poulson 1998)."

In the second category of models, dying people face characteristic spiritual concerns, which may include finding meaning in their illness, the exploration of unrealized goals, guilt, fear of death, anger at God, estrangement, and how they see themselves in relation to a higher power (Connor 1998; Poulson 1998). For some people, addressing these concerns is more central to their well being. For these people, spiritual concerns may be spiritual needs, and failure to address these needs may lead to spiritual suffering. Derrickson called the process of addressing spiritual concerns "the spiritual work of the dying," and identified four categories of this type of work: (1) remembering, as an act of life review or taking inventory, may lead to the discovery of a deeper meaning of the patient's life; (2) reassessing, finding meaning in the dying experience, in which one often feels stripped of purpose; (3) reconciliation, the mending of torn relationships; and (4) reunion, the meeting of the living and the dead in a spiritual world (Derrickson 1996).

In the third category of models, the experience of dying may offer many, perhaps unlimited directions for spiritual growth. For example, Byock, a former President of the American Academy of Hospice and Palliative Medicine, identified the following tasks of dying, many of which are spiritual (adapted from Byock 1997; Connor 1998: pg. 148-152)

> **Tasks for the End of Life**
>
> Sense of completion with worldly affairs: Transfer of fiscal, legal, and formal social responsibilities.
>
> Sense of completion in relationships with community: Closure of multiple social relationships (employment, commerce, organization, and congregational).
>
> Sense of meaning about one's individual life: Life review – the telling of one's stories; transmission of knowledge and wisdom.
>
> Experienced love of self: Self-acknowledgment and self-forgiveness.
>
> Experienced love of others: Acceptance of worthiness.
>
> Sense of completion in relationships with family and friends: Reconciliation, fullness of communication, and closure in each of one's important relationships.
>
> Acceptance of the finality of life, of one's existence as an individual.
>
> Sense of new self (personhood) beyond personal loss.
>
> Sense of meaning about life in general.
>
> Surrender to the transcendent, to the unknown: Letting go.

Byock presented these tasks within the context of "dying well." This process does not occur in isolation at the end of life, but is the continuation and culmination of a lifelong process. Each person's progression through these tasks is unique; the order in which they are to be accomplished is not rigid, and each person reaches his or her own endpoint.

Other growth experiences include attaining the re-emergence of the soul (Dass and Vaughan 1998). Ram Dass, a best-selling author and behavioral psychologist, described his work with the dying:

> Because I work quite frequently with people who are dying, I watch again and again the way in which their egos take them to a certain place, and then the will runs up against nature. At moments, if the conditions are right, there is a letting go of ego structure, and there is the birth or re-awakening of the soul. And the people come out as if coming out of a shell, and there's a radiance and beauty in that period of time (Dass and Vaughan 1998).

Confrontation with death, with the reality of impending annihilation, leads to re-examination and re-evaluation of one's world view. Spiritual relationships, beliefs, and experiences are formed anew, and the spirit grows.

Dass's description of the spiritual experience of dying may in fact lie somewhere between a growth and a developmental model, a fourth category of models. In contrast to growth, which has connotations of inevitability and continuity, development generally implies a progression between discrete stages. Dass seems to imply that letting go of the ego and emergence of the soul are stages one may attain under the correct circumstances. Two more clearly developmental models will be presented.

First, although Kubler-Ross's stages of dying lie more within the realm of psychology than spirituality, her work is worth mentioning because of the enormous influence it has had on the development of spiritual models. She identified five sequential stages of dying. These are denial and isolation, anger, bargaining, depression, and acceptance (Kubler-Ross 1969). Kubler-Ross's model has been criticized for its rigidity, assumed teleological progression to acceptance, and lack of supporting research (cf. Churchill ; Connor 1998).

Fowler, in Stages of Faith: The Psychology of Human Development and the Quest for Meaning, argued for a developmental model based on the works of Piaget and Kohlberg (Fowler 1981). Faith, analogous to what I describe as spirituality, was described by Fowler as the meaning-making experience in relation to ultimate concerns. Fowler's research was based on 400 subject interviews. Faith development, in his scheme, was promoted by an interaction between an active subject and a dynamic environment. Often, developmental landmarks recognizable from psychology correspond to periods of transition to a new stage. Suffering in particular leads one to reexamine one's beliefs and values. New concepts of relationship and meanings emerge, and one progresses to a new stage of faith. Fowler eschewed the linear and hierarchical nature of Kohlberg's stages of moral development (Gleitman 1986). Instead, Fowler proposed a spiraling model of faith development. Each new level is not a replacement of the preceding stage, but a strengthening and building upon it. Past experiences are re-examined in terms of emergent beliefs and values.

What is Hospice?

A Brief History

The first hospices were established during the crusades as places of healing for all people, including those with incurable illnesses (history adopted from Bradshaw 1996; Connor 1998). The Knights Hospitallers of St. John of Jerusalem cared for travelers going to and from the Holy Land, as well as the sick and the dying. The Pope recognized the Knights Hospitallers as an official military order in 1113. It was not until the 17th century, however, that the origins of the modern hospice movement were established. The Sisters of Charity, first in Paris, then Dublin, and finally in 1900 in London, established hospices to care for the sick and dying poor. In 1952 Cicely Saunders came to work at St. Christopher's Hospice in London, and the modern conception of hospice was born. She is considered to be the matriarch of the modern hospice movement. Saunder's hospice, based on the medieval Christian tradition of caring for the sick, the poor, and the dying, was the first hospice to provide modern medical care exclusively for the terminally ill. Saunders envisioned a model of care that utilized a coordinated team approach to caring for the total needs of dying patient. She stressed excellence in care and a Christian mission of compassion. The following is from the Aim and Basis Statement of St. Christopher's hospice (Saunders 1986):

> St. Christopher's Hospice is a religious foundation, based on the full Christian faith in God, through Christ. Its aim is to express the love of God to all who come, in every possible way; in skilled nursing and medical care, in the use of every scientific means of relieving suffering and distress, in understanding personal sympathy, with respect for the dignity of each patient as a human being, precious to God and man. It is planned that the staff should form a community, united by a strong sense of vocation with a great diversity of outlook in a spirit of freedom.

The hospice movement in the United States has been criticized for moving away from this Christian mission to a more secular base (Bradshaw 1996).

Hospice was established in the United States in 1971. The National Hospice Organization was formed in 1978. In contrast to the hospice movement in the United Kingdom, hospice in the United States had a larger focus on home care and volunteerism (Connor 1998). In 1982, Medicare added hospice care to its list of benefits. The hospice movement took off. The hospice population grew from 158,000 in 1985 to 246,000 in 1992 (Lattanzi-Licht and Connor 1995, the National Hospice Organization census was not conducted until 1985). Standardization became essential, and in 1987 the Standards for a Hospice Program of Care were first published. They were subsequently revised and reprinted in 1993.

In the United States, Medicare provides a hospice benefit for patients diagnosed by a physician with less than six months to live. Once a patient is enrolled, hospice is expected to provide all of the care for the patient. This care ranges from intermittent nursing care to pharmaceutical costs to chaplaincy to acute care in the hospital. Admission criteria and what services will be provided have been enormously influenced by Medicare benefit criteria (Lattanzi-Licht and Connor 1995).

In 1996, approximately 40 percent of hospices were independent corporations, 37 percent were divisions of a hospital, and 21 percent were divisions of a home health agency (Connor 1998). In 1992, 37 percent of all people who died of cancer and 31 percent of those with AIDS died in hospice. At that time non-cancer patients comprised 22 percent of the hospice population. That number rose to 40 percent in 1995. In 1996 there were 2,914 operating hospices in the United States, 90 percent of which were Medicare certified. Medicare reimbursement accounts for 74 percent of hospice income. The mean length of stay in hospice was 52 days in 1995, however the median length of stay was 29 days in the same year. One San Francisco based hospice reported that median time from admission until death fell from 35 days in 1996 to 19 days in 1997 (Borden 1998).

Increasingly, hospices are merging, forming partnerships, and seeking managed care contracts. In 1996, 43 percent formed partnerships with other agencies – 45 percent of these with home health agencies and 41 percent with other hospices. Furthermore, 61 percent of hospices had contracted with managed care.

Characteristics of Hospice

Characteristics of hospice care have been stated in multiple ways (Lattanzi-Licht and Connor 1995; Ackerman 1997; Connor 1998). The most recent and complete description is in Hospice: Practice, Pitfalls, and Promise, by Connor (1998). The following are adapted from Connor's list:

1. The patient and family are the unit of care. Family is taken generally to mean those bonded to the patient by blood or emotional ties.

2. Care is provided in the home and in inpatient facilities. Hospice allows people to die where they want. Most people prefer to die in their homes.

3. Symptom management is the focus of treatment. Hospice patients understand that there is no definitive cure for their illness. Hospice care is directed at treating the symptoms, not curing the disease.

4. Hospice treats the whole person. Hospice care is designed to address the physical, social, psychological, spiritual, and practical needs of dying patients.

5. Services are available 24 hours per day, 7 days per week. Although hospice usually does not provide 24 hour care, hospice staff are always on call.

6. Hospice care is interdisciplinary. The hospice team includes physicians, nurses, social workers, mental health professionals, chaplains, therapists, and volunteers.

7. Hospice care is physician-directed. The patient's attending physician must determine that the patient has an incurable condition with a limited life expectancy. The hospice medical director oversees the care of all hospice patients and supplements the services of the attending physician.

8. Volunteers are an integral part of hospice care. Often they have appreciated death in their lives and appreciate how hard it is for families to handle difficult situations.

9. Services are provided without regard to ability to pay. Hospices do not deny services on the basis of need.
10. Bereavement services are provided to families on the basis of need. Hospice provides a program of bereavement support for at least a year following the patient's death.

Definition of Spiritual Care

Literature on what constitutes spiritual care is abundant. Spiritual care can be divided into three modes of care: meeting basic needs, direct chaplaincy, and the creation of a caring, loving community.

The National Hospice Organization (NHO), in *The Standards of a Hospice Program of Care* (1993), stated:

> Hospice exists in the hope and belief that through appropriate care, and promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation that is satisfactory to them (Lattanzi-Licht and Connor 1995).

What does it mean to be "free" to prepare spiritually for death? One framework from which we can view this idea is within the field of humanistic psychology. Abraham Maslow described a hierarchy of needs, in which certain higher needs could not be addressed until more basic needs had been met (1968). In this context, before one can develop spiritually, other more basic needs such as the relief of pain must be met. Thus, the first mode of spiritual care is providing freedom to address spiritual concerns by meeting more basic needs.

The second mode of spiritual care is the more traditional care provided by hospice chaplains. This type of care includes religious rituals conducted with and for the patient. Examples of rituals include praying with patients, laying on of hands, and anointing. Interestingly, only one out of three or four patients in a local hospice accepted chaplain visits (Perrino 1999). Chaplaincy varies greatly among hospices, with some hospices having their own chaplaincy staff and others contracting with local clergy. Hospices attempt to be inclusive and open to people of all religious backgrounds.

The third mode of spiritual care is delivered by all hospice staff, and is characterized by the creation of a caring, loving community. All hospice staff are encouraged to provide this form of spiritual care. This community provides spiritual care by listening, touching, loving, encouraging the expression of feelings, respecting a patient's right to their individual way of dying, and encouraging them to tell their stories (Perrino 1999). Lunn wrote that a listening presence is one of the essential components of spiritual care (Lunn 1993):

> The patient usually needs the combined presence of a team that goes beyond their particular skills and funtions. It is skill and competence with a deeply human presence that is needed ... Presence at its purest is *being* rather than *doing*, so the greatest test is whether we can just sit with people in their pain, with their suffering and unanswerable questions.

Cicely Saunders wrote (quoted in Burns 1991):

> This is indeed a place of meeting. Physical and spiritual, doing and accepting, giving and receiving, all have to be brought together ... The dying need the community, its help and fellowship ... The community needs the dying to make it think of eternal issues and make it listen.

Criticisms of Hospice

Although hospice claims to provide holistic care, including spiritual care, there is some debate within the palliative care community about the legitimacy of this aim. The goal of palliative care is the relief of patient's suffering. Randall and Downie, in Palliative Care Ethics (1996), asserted that spiritual care is an extrinsic goal of palliative care and should not be confused with the intrinsic aim of health care in general which is to bring about a medical good. A medical good was described as, "something that can never be precisely or completely analyzed but we are using it as a blanket term to cover medical treatments such as those which lead to the amelioration or sometimes cure of a disease process, the relief of suffering, the prolongation of life, the dressing of wounds or injuries and many others (p. 14)" The authors contended that palliative care does not represent a separate form of health care, but is a subset of all health care. The authors recognized that spiritual issues may arise in the delivery of the medical good, owing to the unique relationship that exists between physicians and patients. A physician in this situation might be able to care for the patient in this situation with genuine, compassionate listening. However, the authors contended that spiritual care of this sort cannot be taught, and therefore cannot be intrinsic to the care physicians offer terminally ill patients.

Furthermore, Randall and Downie argued that physicians should not even assess a patent's spiritual needs(1996). Case examples were used to illustrate their point. A physician might assume that a patient needs to work through an emotional "hang-up." This perception may be accurate or not. In either case, the patient may be too exhausted or unwilling to confront this "hang-up." The authors contended that there is a danger of distressing and thus harming the patient by forcing him or her to address this concern. Furthermore, they point out that if hospice advertises both spiritual and instrumental care, patients who are not interested in spiritual care may accept it in order to receive relief of physical suffering.

In an article in the Cambridge Quarterly of Healthcare Ethics, Ackerman was harshly critical of several aspects of hospice care (1997). First, she asserted that hospice dogmatically urged patients to accept death as natural. She argued that patients should be free to "Rage, rage against the dying of the light" as Dylan Thomas wrote. Second, she found that by using the patient and family as the unit of care, hospice in some instances unfairly violated patients' best interests at the end of life. Third, she argued that by insisting that spiritual and psychological care are as important as physical care hospice may harm patients. Patients may be forced to discuss concerns they are not prepared for or interested in discussing. Finally, Ackerman found that hospice unfairly limits its care to those patients who are interested neither in suicide nor life-sustaining treatment. She described this as the "Goldilocks Principle ... death by assisted suicide is too soon, death after high-tech life-prolonging treatment is too late, "natural" death is just right."

Spirituality as the "Ignored Dimension" of Hospice Care

A dearth of research in the spiritual aspects of hospice care led one author to label it the "ignored dimension" of hospice research (McGrath 1997). Numerous authors have called for more research in this area (O'Connor 1986; Millison 1995; Babler 1997; McGrath 1997; Connor 1998: pg. 177). Primarily quantitative research has been conducted (Millison 1995; Babler 1997). This quantitative research uses scales to asses a patients spirituality, such as the Spiritual Well-Being Scale, the Purpose in Life Test, and the Spiritual Perspectives Scale (Millison 1995; Babler 1997). Multiple studies find hospice care deficient in providing spiritual care (Ley and Corless 1988; Babler 1997; Reese and Brown 1997). Findings of these studies indicate that spiritual care was more likely to be provided by spiritual care professionals, secondly by nurses and least likely by social workers (Babler 1997; Reese and Brown 1997). The ability of physicians to provide spiritual care for hospice patients has not been studied. Quantitative research has elucidated the degree to which dying patients are concerned about specific spiritual issues, but has failed to elaborate more specifically what the relationships between these concerns are, how these concerns relate to the care dying patients receive, and what these spiritual concerns are from the dying patients' perspective.

Although many theories have been generated regarding the spiritual experience of dying, several authors have been critical of the lack of research to support these findings (Churchill ; Connor 1998: pg. 47). Furthermore, quantitative research that has been conducted employs a preconceived theory or hypothesis of the spiritual experience of dying or of the nature of spiritual care in hospice. Qualitative research, in approaching the data without preconceived hypotheses, develops theory from the lived experience of dying patients.

Chapter Three: Methods

Data for this research came from a study titled “Exploring the Transition to Terminal Illness.” This study’s principle investigator is Jeff Burack. The study received funding from the Project on Death In America Faculty Scholars Program. Human subject approval was obtained from the University of California at Berkeley by Burack. The project is described as “...a retrospective, multi-perspective clinical ethnography aimed at providing a phenomenological description of how patients come to be identified as terminally ill, and how those who care for them accomplish and understand the transition from primarily curative to exclusively palliative care (Burack 1998).”

The sample for this study were hospice patients, their primary caregivers, and primary physicians. Data were collected using semi-structured qualitative interviews. Interviews were tape recorded and the data transcribed. Researchers wrote reactions and descriptions for some of the interviews. Descriptions and transcripts were analyzed.

Data were analyzed using a grounded theory model first developed by Glaser and Strauss (1967). The central tenet of this methodology is the development of theory grounded in the data. Data are approached without preconceived hypotheses or theories. Grounded Theory is a systematic approach to social science research, requiring the researcher to be creative and open-minded (Lofland and Lofland 1995).

Interviews were first read without notation. Individual subjects were described utilizing four main categories: a general description, a description of the interviewee’s spirituality, the background or story of the interviewee, and an initial interpretation of the interview. Interviews were read a second time and coded as new categories emerged. After three interviews had been analyzed, some codes were collapsed into broader categories and themes. All data were then analyzed in terms of these emerging themes. Data were repeatedly re-examined to determine the fitness of new themes as they arose from the data. After several cycles of analyzing, the themes were organized into two charts, one describing the relationship between spirituality and dying, and the second describing how hospice care fit into this relationship. Themes were used to generate a theory.

Hospice patients were recruited from four Bay Area hospice agencies. These were Hospice by the Bay, Hospice of Contra Costa County, Pathways Hospice, and Kaiser Hospice. Two of the patients contracting with Hospice by the Bay lived in Zen Hospice, a residential hospice. All other patients received home hospice care. Interestingly, the two patients in the residential hospice, Mr. Zaragosa and Mr. Pichet, together with Mr. Dobson, who eventually moved to Zen hospice, represented the most socially isolated patients of the study. Interviews from nine patients, three physicians, and one caregiver were included in this study. Due to time constraints, in most cases only the initial interview with each patient, physician, and caregiver were used for the study. In some cases, multiple interviews with the same patient were used to track changes over time. The ages of patients ranged from thirty-seven to eighty-seven years. Seven patients had cancer, one had AIDS, and one had Chronic Obstructive Pulmonary Disease. Due to the nature of the patient population, some patients may have experienced diseases which affected their cognition or mental status. Names of subjects have been changed to preserve confidentiality.

Chapter Four: Findings

Overview

The results will be expressed as the themes that emerged from the data. Quotes from the interviews are presented to illustrate themes. Quotes have been edited for clarity. The research questions were:

- What is the spiritual experience of dying?
- What role does hospice play in the spiritual experience of dying?

Three themes emerged from the data in response to the first research question. These were:

- Finding meaning or purpose in dying.
- What happens after death?
- Resolving relationships, forgiveness and reconciliation.

These themes raised issues that ranged from concerns to needs. A concern is something that might provoke anxiety, but does not necessarily lead to suffering if not addressed. A need, on the other hand, is something that is so integral to that person that not meeting the need leads to suffering.

The role of hospice in the spiritual experience of dying was examined from three perspectives: patient, caregiver, and physician. From the patient's perspective, meeting basic needs emerged as the overwhelming reason that patients entered hospice. Other reasons for joining hospice included economic reasons and the fact that hospice provides a dying at home alternative to dying in the hospital. Although, as was stated in the literature review, meeting basic needs can be considered a form of spiritual care, patients did not state that they joined hospice for spiritual care. When asked how hospice met their needs, most patients did not suggest that hospice provided spiritual care. However, the creation of a loving, caring community and hospice chaplain services did arise as a theme in a subset of patients.

One caregiver interview was studied. This caregiver discussed her hope that by relieving her of care-giving responsibilities, hospice would provide the freedom for her to be more of a daughter to her mother. The three physicians interviewed lost touch with their patients in varying degrees once they made the transition to hospice care. These physicians saw a diminished role for themselves in the medical care of their patients. Physicians struggled to find a new role for themselves caring for patients on a human level. However, two of the three physicians expressed discomfort in providing spiritual care for patients.

What is the spiritual experience of dying?

Finding meaning or purpose in dying

A resounding theme that arose from the data was that dying patients sought and found meaning or purpose in dying. For some patients this meaning or purpose was formulated prior to entering hospice, but for many, meaning making was clearly an ongoing process in hospice. Interestingly, meaning in dying found by patients was often unique.

For some, dying was a time to tend to the spiritual. For Mr. Pichet, a talkative, thin, fifty-one year old Cajun man with lung cancer, dying provided the opportunity to "put [his] spiritual house in order:"

> I think this is like a double blessing. You know? On one way it's a downer cuz, you know, hey, look I'm here ready to kick the bucket. But on a second hand, that's a blessing. You get a chance, like I said, to put your spiritual house in order ...

Although “it’s a downer” that he’s “going to kick the bucket,” Mr. Pichet felt himself doubly blessed that he knew when he would die and had the time to prepare himself spiritually. Mr. Zaragosa, an effeminate, soft-spoken, Guatemalan man with AIDS believed he gained spiritually from his suffering:

> I suffer a lot with my body. It is my body who is tired. But not my soul. My soul gains from the disease more ... It gains more to love. To love myself and to love and appreciate people and appreciate life the way it is.

For both Mr. Pichet and Mr. Zaragosa, dying was an opportunity to tend to the spiritual. For Mr. Zaragosa, this culminated in spiritual growth.

Another meaning found in dying was the opportunity to pass on wisdom gained from life experiences. Mrs. Wright was dying from emphysema, a disease brought on by years of smoking. She spoke in short stretches punctuated by frequent breaks to catch her breath. Mrs. Wright made it her personal quest to educate others about the dangers of smoking and the misery of the inexorable decline of emphysema.

> I have written many, many ‘To whom it may concern’ letters regarding emphysema. I’ve spoken of the expense of the trial, the futility. I have endless reasons not to take one small puff - it’s dangerous, dangerous, dangerous, dangerous.

Mrs. Wright agreed to be interviewed in part to spread this message:

> I hope that those who listen perhaps to this recording will take a second thought and spare themselves the agony of going down, down, down, down until they’re terribly horribly helpless

Though letter writing and interviews with the press, Mrs. Wright was determined to pass on lessons learned hard in her life. Mrs. Wright found hope in her mission; vitality in her purpose.

Mrs. Rose found meaning in bearing her suffering and her lifelong mission of spreading the gospel. Mrs. Rose was an affectionate, deeply Christian, eighty-five year old woman with liver cancer. She liked to give hugs when saying hello and goodbye. She frequently referred to herself and to the Lord, as if they were working together on everything. She believed that, like Jesus, everyone has a burden to bear:

> When I was first told that my days were limited, yes, I cried. I didn't cry out loud or worry some or anything. I had a little quiet cry. You know? And that was about it. You have to accept what is given you in life. Eventually it's going to be given. Whether you're a Christian or non-Christian, you're still going to have to face some sort of thing in life because everybody does.

She believed that even in sickness, she existed for a larger purpose – to be good to others and to spread the gospel:

> I figure that the Lord is keeping me here because he's got jobs for me to do, and some of them come up in this sickness. There's been many people that have learned to believe in Jesus just by me talking.

When Mrs. Rose refers to God "keeping her here," she is referring to her belief that she has been cured of cancer. Mentioned in passing at the first interview, this belief became a major theme in a second interview with Mrs. Rose. In light of her initial statement, that she "accepted" her prognosis, this denial of dying illustrates the complexity and non-linearity of Mrs. Rose's spiritual path. And interestingly, Mrs. Rose was interested in both hospice care and curative care, seemingly contradictory modes of care under current hospice standards.

Mr. Graham derived meaning from contributing to progress. A former dean of a major professional school and a distinguished researcher, Mr. Graham was proud of his accomplishments:

> I think life has a purpose. Otherwise it would be stupid. And I'm a great believer in progress, we're better now than we used to be ... I think just on the whole we're making progress. I'm glad I lived when I lived. I enjoyed my life. I think I had tremendous advantages as I came to a life where I was expected to make things better, and I expected to take responsibility, and I assumed that I had to take responsibility. And I did. And it paid off. And I consider that the world is better because I lived in it.

Mr. Graham no longer felt that he was contributing. Although he had a cancer that could potentially be treated to extend his life several months, he saw no point in living longer. "But I've enjoyed life, and I feel like I - and even if I lived twenty or thirty more years, I wouldn't make any more significant contribution than I already have." The meaning that Mr. Graham perceived in dying was not straightforward. For Mr. Graham, the purpose of dying was the end of a state without the capacity to contribute. In a sense, Mr. Graham found meaning in dying as the end to a meaningless state.

What happens after death?

When asked about their spiritual beliefs, patients often took spiritual beliefs to mean beliefs about what happens after death. Patients came to hospice with beliefs about what happens after death, and when asked if their spiritual beliefs had changed since entering hospice, patients responded that they had not. Most patients thought about what would happen to them when they die more than they had before they were terminally ill. When asked how often they thought about their spiritual beliefs about death, patients answered that they were "thinking about it a lot," "wondered" about what happens to them after death, or were "far more religious than before." Spiritual beliefs about what happens after death could be most easily grouped into two groups: (1) variations on traditional Christian beliefs and (2) secular beliefs.

Mr. Pichet, a Catholic, believed that he would become an angel in the afterlife:

> I believe in God ... I do believe that He created Jesus and that Jesus is his only son and that he did die on a cross, and he did die for our sins, and that through the blood of Jesus Christ that we all can be saved, and that in the next life we'll all be different. We won't know each other. I won't know my sisters and my brothers or my daughters or anybody, because I'll become like an angel. You know? I won't have no pain or nothing.

Mr. Zaragosa, another Catholic, believed that he would meet his "soul match" in Heaven. He described his soul match as a being who looked after him from a non-corporeal state. The soul match got to know him well by smelling him. When he was doing drugs and alcohol, the soul match became "angry and jealous." When he was taking care of himself, the soul match came closer to him. He believed that after he dies he would be reunited with his soul match in a place without sound, names, and memories. A third subject, Mrs. Rose, a Protestant, found comfort in her beliefs about the afterlife:

> I think I have prepared myself for knowing that we do live, and if you're a Christian, you go to live with the Lord later on in life, and you don't have too much to worry about - you're supposed to have all goody things. Do I know exactly? No, nobody does ... But depending on how you believe makes all life easier. A lot easier. People that don't have it, I don't know how they handle it really.

Other patients described secular beliefs about what happens after death. Mrs. Thompson believed that she would retain an immortality in the thoughts of those she left behind.

> I think for me immortality is true ... if there's anything good that I have done, maybe Josh will remember that and do it for somebody else, and that way ... I continue to live on one way or another ...

Mr. Dobson saw dying as a metaphysical joining of souls:

> I believe that there may be some form of energy ... that takes us all toward an ending and it joins, hooks up with more and other souls and it moves around for eternity. I don't know about whether or not there's anything to be said about reincarnation or for believing that I'll see my loved ones when I die. I'm not sure about that. I'll wait and see.

Like Mr. Dobson, many patients expressed uncertainty about whether they would retain a conscious reincarnation or afterlife. Mr. Graham questioned his Christian belief in an afterlife, proposing an alternate secular explanation for what happens after death:

> I may have a conscious afterlife, or I don't know. If I have a conscious afterlife, that's so many brownie points to the good. If I don't have, it's no great loss. Because there'll be lots of people thinking about me afterwards.

Like Mrs. Thompson, Mr. Graham saw a non-conscious immortality living on in the accomplishments of his lifetime and in the thoughts of others.

Within the group of Christian patients, wide variation among beliefs about the afterlife existed, even among patients of the same denomination. Each individual's spirituality was unique, regardless of religious background. Both secular and non-secular patients found comfort in a belief in an afterlife, whether it was conscious or non-conscious. Spiritual concerns about what happens after death was a commonality among both secular and religious patients.

Resolving relationships, forgiveness, and reconciliation

Patients struggled to resolve relationships with others. They were compelled to forgive and seek forgiveness, and to find reconciliation with loved ones. Mr. Zaragosa, for example, felt guilty about possibly having given AIDS to other people both through needle sharing and unprotected sex:

> My years of drinking I did feel a little guilty because I know I was having unsafe sex. And once in a while when I share needles, some of those guys

> never clean it. They don't. They just stick it. And now that I did it, I can count that it is like maybe ten times that I did it in all of my using. That is not that much for many years. But in those ten times maybe half of those people never, and I let them to do the same thing to me ... I don't care. And now I think that is horrible. They already taught us don't do it and we did it.

Mr. Zaragosa made frequent reference to the language of the Catholic Church in saying that he was a lost child and God found him and forgave him. By repeatedly insisting that God forgave him, Mr. Zaragosa ended-up sounding as if he was trying to convince himself. This demonstrates the degree to which finding forgiveness was essential to Mr. Zaragosa. Resolving this issue with himself, with his God, and with others was a matter of need, not merely concern.

Mr. Pichet likewise needed to resolve a relationship. The first time I interviewed Mr. Pichet, he said that what he feared most was dying with hate in his heart. He also talked about the anger he felt for his estranged son and his struggle to forgive him. Mr. Pichet was furious at his son for not listening to his advice and for cursing him. Mr. Pichet said that he hoped to write a letter to his son forgiving him. The second time I interviewed Mr. Pichet, he was clearly agitated by the issue. When I raised the subject, Mr. Pichet climbed out of bed and launched into a tirade expressing his anger and frustration with his son. He threw on the bed four unfinished and unsent letters to his son. The third time I interviewed Mr. Pichet, he refused to talk about the issue. I interviewed Mr. Pichet a fourth time. Almost right off the bat Mr. Pichet proudly declared that he had taped a message for his son:

> I might be gone, but he got his little message. At least he can deal with it down the road. If he ever has hesitation, maybe I should have dealt with my dad, maybe I should have made peace with my father ... He will have through the route that I have given him forgiveness verbally over the

> phone; and he can plug it in and the whole world and god and everybody can hear that I did love him.

Mr. Pichet's struggle toward reconciliation represented the most compelling example of spiritual growth. Mr. Pichet's path was not one-dimensional; his spiritual growth belies any concept of stages, where individuals progress from one discrete stage to the next. Mr. Pichet initially seemed more comfortable forgiving his son than he felt in subsequent interviews. Eventually, although clearly not completely resolved with his son, Mr. Pichet had achieved a sense of completion in this relationship that he was satisfied with. Recall that Mr. Pichet stated that dying provided him with the opportunity to put his "spiritual house in order." This finding of meaning is a stage that some developmental models would place before reconciliation. Spiritual growth seems to be complex and non-linear, characterized by ups and downs, progressions and regressions.

What is hospice's role in the spiritual experience of dying?

Patient and caregiver perspectives

A logical assumption, given hospice's claim of providing spiritual care for the dying, is that patients may have joined hospice in part to receive this care. This study's findings do not support this assertion. Patients' descriptions of hospice developed into four themes: (1) hospice provides for basic needs, (2) hospice is economical, (3) hospice offers a natural death alternative to painful, futile treatment, (4) hospice provides a caring, loving community, and (5) hospice is home care.

Hospice provides for patients' basic needs

The overwhelming theme that emerged from the data is that hospice provides for patients' basic needs. These needs ranged from assistance with everyday activities like taking a bath and shopping to instrumental care such as adequate pain relief or relief of dyspnea. The following are examples of patient responses to the question: Why did you think hospice would be right for you? Rose said, "Well, not too much except that I would have constant care. I would have a nurse come every week. I'd have somebody, she comes and cleans house for me for half a day. And that's about it." And Mrs. Thompson stated, "I found myself being uneasy taking a bath alone without anyone here. I felt it would be so easy to slip. My strength has been going down." And Mr. Zaragosa, who had moved into a residential hospice, noted, "... you don't have to worry about food."

Mr. Pichet, also residing in a hospice facility, found that by taking care of his basic needs, hospice allowed him to concentrate on getting healthy.

> ... at that other place I was up on the third story. Here they'll bring dinner up for me. It's made sure that I've got three nutritional meals a day plus Ensure. I don't have to worry about going to Safeway, getting everything up to the third floor, doing the laundry or anything like that. So all I have to do here is eat and get healthy.

Interestingly, Mr. Pichet and Mr. Zaragosa experienced dramatic improvements in their health upon entering hospice. These two patients of low economic status were two of the more socially isolated individuals in the study. Their basic needs had been neglected to a much greater extent than for other patients prior to entering hospice.

From the caregiver's perspective as well, meeting basic needs emerged as the central expectation of hospice care. Mrs. Chambers was Mrs. Rose's caregiver. By meeting Mrs. Rose's basic needs, Mrs. Chambers hoped that hospice would facilitate the creation of a caring, loving, listening relationship between a mother and a daughter:

> I didn't want the struggle of the demands of care-taking to take away my being a daughter, which I hope eventually I will be able to be a daughter. Instead of the person that has to do all the errands, because you could get

> too busy, and you're no longer really in relationship. I would rather sit and read her the Bible and hold her hand and be an encourager to her to take her out for a drive, do the things that other people probably don't have time for. That's what I would like to be doing. That's kinda my goal in life.

Mrs. Chambers hoped hospice would provide for her mother's basic needs, and by doing so, free Mrs. Chambers to engage in a caring, loving mother-daughter relationship.

Hospice is economical

Mr. Zaragosa's story revealed another theme that emerged as a reason to join hospice – that of economics. After comparing his life in a live-in hospice to life in his former quarters in a residential hotel in the Tenderloin, one of the poorest districts in San Francisco, Mr. Zaragosa exclaimed, "What do I want to do living there in the hotel for five hundred and five fifty?" For patients with little income, hospice was an inexpensive route to home care. Mr. Graham remarked, "Well, the big advantage to hospice was that a nurse would come once a week, and they would keep good track of me, and reduce the costs..."

Hospice offers a home death alternative to painful futile treatment

Patients felt that in contrast to hospitals, hospice would allow a natural death at home. Mrs. Thompson observed:

> Well, I never wanted to be in a hospital. I mean I've done that. When I was working in the city with the elders, I learned more about hospice and that I could stay home and be cared for ... my husband spent his last years of his life in a convalescent hospital, so I wasn't anxious to go through that, go down that road.

Other patients were similarly disturbed by personal experiences of death in the hospital. Mr. Graham, like Mrs. Thompson, was aware of hospice before becoming terminally ill. Mr. Graham described his first conversation about hospice with his physician:

> We had a long discussion about alternatives, chemotherapy and all the rest of it ... And he just suggested in his opinion that at my age, 86, that I've lived a full life and that I could go into the hospice program, I could have probably six months to a year of fairly comfortable living, pain free, with some limitations on my activities, but not a great deal, or I could have chemo and I'd feel like hell most of the time [laughs]. I wouldn't want to do anything, so I didn't think there was any choice.

Most patients first learned of hospice when given their terminal diagnosis. Often it was the physician who first explained hospice care to patients. Hospice was presented by physicians as the alternative to painful and likely futile treatment. Mr. Dobson, on the other hand, did not recall the specifics of how he came to be in hospice: "One day, two nurses came in and told me who they were, the Hospice by the Bay, wonderful people, and they understand the choice I've made to just allow nature to take its course." Confusion about how the transition to hospice care took place was not unusual.

Hospice provides a loving, caring community

For a subset of patients, hospice provided forms of spiritual care other than caring for basic needs. Interestingly, these were Mr. Pichet and Mr. Zaragosa, who resided in hospice, and Mr. Dobson, who eventually moved into a residential facility.. As mentioned, these patients were also the most socially isolated of the study. Mr. Pichet was the only patient to mention meeting with a chaplain. However, when asked if his chaplain provided spiritual care, Mr. Pichet responded that the spiritual care he received from his chaplain was minimal. He stated that a priest that visited him and the staff at Zen hospice provided more spiritual care than the chaplain. These patients were the only patients to associate hospice care with a caring, loving community. Mr. Pichet stated that, "They truly care about me as a person." Mr. Zaragosa enjoyed being taught to meditate and to paint. He found that these activities helped him when he observed, "So I don't have to think and sit here all the time thinking about AIDS." Mr. Zaragosa additionally contrasted the loneliness of the hospital with the community of hospice.

Hospice is home care

A somewhat startling theme that arose was that for patients receiving hospice care in their home, hospice was not about care for the dying. For these patients, hospice was an organization that provided home care, not palliative care. Home care, unlike hospice care, is a service that simply provides medical care in the home, such as intravenous medications or dressing changes. Home care is not specifically for dying patients, and home care does not share the hospice philosophy of providing not just physical but spiritual support.

The majority of patients were in home hospice. Among these patients, descriptions of hospice sounded little different from how home care might be described. Among some patients, hospice was even confused with home care. Mr. Gaetani, an eighty-three year old man dying of lymphoma, joined hospice when the organization providing his home care went out of business. He stated that his doctor "just put me in here when the other one closed up." Mr. Gaetani appeared unaware of any difference between his former home care organization and hospice. To Mrs. Rose, hospice was an organization that tried to cure people of disease. When told that hospice is generally an organization for people with less than six months to live, she stated, "I don't think that's true." Even among patients that understood that hospice was for the terminally ill, patients' descriptions of hospice sounded like home care. For the dying, outpatient hospice was home care.

Physicians' perspective

Physicians saw a greatly decreased role for themselves medically after patients made the transition to hospice care. Dr. Chen, Mr. Dobson's physician, noted that hospice was doing a good job of caring for her patient medically:

> I think it's because someone else is taking care of him. Once or twice I tried 'Well, how is your pain? What regimen are you on now?' And then he'd have to go collect his bottles and tell me, and [I thought] 'Well, what's the point? Why should I document down 30 milligrams qd and 25 patch,' It just didn't seem very important that I know what his regimen is or how to tweak it since somebody else was doing a pretty good job of that.

The other two physicians noted that their role had been restricted to signing paperwork and filling out forms. Dr. Wilcox, Mr. Zaragosa's physician, explained that he had patients in hospice with whom he developed only a paperwork arrangement:

> The hospices want everybody to have an identified primary care provider to provide prescriptions and to sign forms and all that kind of stuff. And so I think to some extent it can become like a paperwork kind of arrangement.

Physicians struggled to find a role for themselves as carers for their patients outside of this paperwork arrangement. This form of care they aspired to provide can be called: Meeting patients on a human level. Dr. Lewis, a physician, stated that his role was to listen to Mrs. Rose and to assure her that she would be comfortable. When asked if he saw a role for himself providing spiritual care for Mrs. Rose, he replied:

> I think I could be there to help her. I think she could probably teach me some things about coping with death and dying ... I think she's coming to grips with it. I'd be there to listen, I think. What I try to convey with her is more that she's going to be kept comfortable. You know, we'll do everything to keep her out of the hospital and make sure she's comfortable.

Dr. Chen likewise saw herself as more of a friend to Mr. Dobson once he began receiving home hospice care. When asked what her role was in caring for Mr. Dobson, she replied:

> More like a friend ... I think when we talk now there is less talk about his symptoms than about how he is doing, and who he's spoken to that week and when he feels ready to transition into moving into the [live-in] hospice.

Dr. Wilcox stated that he saw himself in less of a medical role when he visited patients in hospice. He stated, "when I go visit I go in just as a person."

Although physicians expressed a sincere interest in meeting patients on this human level, several factors limited in their ability to do so. These mitigating factors included other obligations, a reduced need to see patients for medical reasons, and an era of decreasing home visits. In many cases time demands simply won out. Dr. Chen, a resident physician, perceived that Mr. Dobson felt she abandoned him when he joined hospice. She explained that the huge decrease in contact she had with Mr. Dobson was not intentional, but was rather a matter of conflicting obligations:

> It's definitely a timing thing ... actually his hospice nurse was in contact with me pretty frequently, and I would get pages from her when I was on the Ward, and I remember feeling frustrated; it's difficult for me to make that transition when I'm on the Wards, and here I am hearing about my clinic patient while my team is still waiting for me to finish morning rounds and I remember feeling like 'I can't do this. I can't be the clinic doc and the hospital doc at the same time.' And I also am thinking 'I will call you and Mr. Dobson back at the end of my day' and then always the end of my day would be eight o'clock and then always it'd be too late. I remember feeling at several points like 'I want to do this, I want to do this, but I can't do this.' And then there was also the relief that somebody else was taking care of him. That before it had just been about me and Mr. Dobson and if I wasn't there for him no one would be there for him, and now I felt this tremendous sense of relief 'But Jennifer sees him every day.'

Other physicians similarly found their relationships with patients restricted to phone conversations, and on rare occasions to a home visit. Dr. Lewis stated that he could not justify making a house call to his patient on medical grounds. All three physicians felt they had lost touch with their patients to varying degrees once they entered hospice.

Although physicians struggled to meet patients on this human level, it did not mean necessarily that they felt comfortable attending to patients' spiritual concerns. Both Dr. Lewis and Dr. Chen were uncomfortable addressing spiritual issues. Dr. Lewis stated that he felt much more comfortable addressing medical concerns such as hypertension than spiritual concerns. Dr. Chen explained her position on the subject:

> I don't know necessarily that it's our job, but I certainly think that it would be good care if we could ... How to tap into his spirituality and help him through that is a more difficult question because we have no training at all in how to do that, and so I'm really relying on my own personal history, my own personal views on it to guide me there. Which is why it's been such a hit and miss kind of a project.

Dr. Chen felt that providing spiritual care is a desirable goal, although she is unsure if spiritual care falls within the realm of the physician's responsibility. She was frustrated with her lack of training in the area. Thus, her actions were guided by her own life experiences and beliefs.

Chapter Five: Discussion

This study elaborates the connections between hospice care and the spiritual experience of dying using qualitative analysis of interviews with nine hospice patients, three physicians, and one family caregiver. The findings of this study can be cautiously generalized to other patients in hospice. Patients' spiritual concerns could be grouped into three themes: (1) finding meaning or purpose in dying, (2) what happens after death? and (3) resolving relationships, forgiveness, and reconciliation. These spiritual concerns were important to these patients; for some patients these concerns reached the level of needs. As we saw with Mr. Pichet, not meeting a spiritual need led to suffering and the possibility for spiritual growth.

As important as these spiritual concerns were to these patients, spiritual care was not a reason patients sought hospice care. Rather, patients saw hospice as an economical way to meet their needs for home care. In terms of the three modes of spiritual care described in the literature review, meeting basic needs was the major theme to emerge from the patients' perspectives. Among a subset of patients, hospice was described as a caring, loving community. These patients were both the most socially isolated of the sample and two of the three resided in live-in hospice. For these patients, the transition to hospice care represented a dramatic improvement in their social structure. The loving caring aspects of hospice care were very important to this subset of patients. The majority of patients, however, described hospice as home care. Hospice was an organization that met basic needs of patients, but did not directly address spiritual aspects of care. Similarly, the one caregiver who was interviewed described her hope that hospice would provide for her mother's basic needs, thus freeing her to be more of a daughter to her mother.

Physicians interviewed did not see a medical role for themselves once patients entered hospice care. Physicians saw hospice personnel as having greater expertise in the medical aspects of end of life care. For some patients, the physician's role was limited to signing forms generated by hospice. Physicians struggled to provide more than this "paperwork arrangement," trying to meet patients as a "friend" or "as a person." Physicians described their role once patients entered hospice as being present for patients and assuring them that they would be comfortable.

This human level of care fits nicely into the caring, listening mode of spiritual care described in chapter two. This type of care, however, requires that physicians actually be present with patients. Physicians found making visit to patients difficult without a medical justification. Other factors such as obligations in the hospital, a climate of decreasing home visits, and time pressures led to a decrease in contact between patients and physicians once patients entered hospice care. Furthermore, physicians expressed discomfort in dealing with the spiritual issues of their patients. One physician articulated her belief that providing spiritual care may not be a physician's responsibility, although it may be a desirable goal. She furthermore expressed her frustration at the lack of training physicians receive in this area, leaving her to rely on personal experience as a guide.

In comparing these findings to the literature, areas of agreement and contrast emerged. As discussed in the literature review, theory on the spiritual experience of dying is abundant. Aspects of the four categories of models of spiritual care presented were reflected to varying degrees in these findings. These data present a model that fits most closely with Byock's Tasks for the End of Life (Byock 1997). In addition to the striking similarity between the spiritual concerns of these patients and Byock's tasks, these data describe a spiritual path more closely aligned with Byock's model than with stage theory. Mr. Pichet's struggle to find reconciliation with his son was complicated, non-linear, and characterized by regression as much as progression.

These analyses point to a much more modest role for hospice in the spiritual care of patients than might have been expected from surveying the literature. What struck me in this analysis were the perceived similarities and lack of differences between hospice care and home care. Chaplaincy care was nearly absent from these patients' experiences. In light of the fact that as mentioned, at one local hospice, nearly three-fourths of patients decline to see a hospice chaplain, these data are only moderately surprising. Only a subset of patients characterized hospice as a caring, loving community. All patients expected hospice to meet their basic needs. These needs varied from instrumental care like relief from pain and dyspnea to assistance with activities of daily living like taking a shower and shopping. In some respects, however, meeting basic needs provides spiritual care of a secondary sort.

Isaiah Berlin, in a landmark paper in political philosophy titled "Two Concepts of Liberty," differentiated between what he called negative and positive liberty (Berlin 1969). A negative liberty is something that you are prevented from doing, such as a law that prevents you from speeding. A positive liberty, on the other hand, gives you the power to act, such as the ability to vote to change the speed limit. One way of understanding the treating of basic needs for these patients is in the Maslovian framework discussed in the literature review, where higher needs such as addressing spiritual concerns cannot be addressed until more basic needs have been met. Another is as a negative liberty. In Berlin's framework, unmet basic needs are a constraint that prevents patients from addressing spiritual concerns. What then, are the positive liberties?

I believe that agency to address spiritual concerns can be facilitated by a community that provides a loving, listening presence. Through connection with others, by sharing joys, stories, and concerns with a listening, present, compassionate other, and feeling love, patients find the power to address spiritual issues. I believe it is in this nurturing environment that patients may find the opportunity to grow spiritually. I further believe that it is the responsibility of all care providers, including physicians, to provide this mode of care, particularly at the end of life when the need to address spiritual concerns may be accelerated.

While the data do not refute my beliefs, they do not support them either. I would have expected to find patients suffering because hospice did not represent a caring, listening community. I did not. As discussed, hospice care, particularly home hospice, was rarely described as a caring, loving community. It may have been that patients received love and support from family and friends. Hospice may have freed caregivers to provide this role, as Mrs. Chambers hoped. In fact, if more caregiver interviews were analyzed, I would not be surprised if by meeting patients' basic needs the caregivers were freed to provide a loving, caring community. However, spiritual care in the mode of positive liberties, which directly empowering patients, was not a theme among patient or physician interviews.

These data raise a number of questions for me as a future physician. I agree with Cassel when he remarked:

> It is not possible to treat sickness as something that happens solely to the body without thereby risking damage to the person. An anachronistic division of the human condition into what is medical (having to do with the body) and what is nonmedical (the remainder) has given medicine too narrow a notion of its calling. Because of this division, physicians may, in concentrating on the cure of bodily disease, do things that cause the patient as a person to suffer (Cassel 1982).

I furthermore believe that physicians can be trained to provide compassionate spiritual care, either from physicians who model such care or rotations with Chaplains. I was surprised therefore not to find patients suffering under the care of physicians who viewed their role as primarily providers of medical care to the point that spiritual aspects of care were marginalized in their practice. Physicians operated much more from the perspective of Randall and Downie's (1996) model of intrinsic (medical) and extrinsic (spiritual) modes of care than from Cassel's model of whole person care. It is true that patients may have flourished under the care of a compassionate, caring, listening physician. However, in the absence of this kind of physician patient care, these patients were doing well. Patients did not expect hospice, much less their physicians, to provide spiritual care. Patients were interested in having their basic needs met. These needs were being met, and patients seemed satisfied. What, then, is the role of the physician? What type of spiritual care ought hospice provide?

As unsettling as it is to me, it may be that simply meeting patients basic needs is the best model of spiritual care for dying patients. Perhaps there is not a role for physicians in the spiritual care of dying patients in hospice. If this is the case, then hospice as home care may be a good model of care for dying patients. Furthermore, it may be that this sort of care is appropriate for people at various stages on their spiritual paths, including patients who are not dying. If home care was a good model of care for patients in this study, and no particularly dying-specific model of spiritual care was necessary, it may be that patients who are not dying are being denied a service that could potentially dramatically improve their condition. The lives of several patients in this study improved drastically after the transition to hospice care. Home care may be an appropriate model of care for non-terminally ill as well as terminally ill patients. In the United States, Medicare provides a hospice benefit only for patients with a prognosis of six months. Part of the reason for the establishment of criteria for admission to hospice was the belief that dying required a particular sort of care, tailored to dying patients' needs. Findings here seem to suggest that good care for the dying may be as straight-forward as home-care. Hospice care certainly would have improved the lives of several of these patients if the transition to hospice care had taken place earlier. Several of these patients were interested in both curative and hospice care. Arcane and perhaps arbitrary Medicare criteria may in fact unfairly limit access to only a subset of the population in need.

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