MEADVILLE LOMBARD THEOLOGICAL SCHOOL

PALLIATIVE SPIRITUAL CARE:
A MODEL OF MINISTRY WITH THE TERMINALLY ILL

A PROJECT
SUBMITTED TO THE FACULTY
OF MEADVILLE LOMBARD THEOLOGICAL SCHOOL
IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS OF THE DEGREE OF
DOCTOR OF MINISTRY

BY
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CHICAGO, ILLINOIS
JUNE, 2006

MEADVILLE LOMBARD THEOLOGICAL SCHOOL

CHICAGO, ILLINOIS

FACULTY APPROVAL PAGE

DOCTOR OF MINISTRY FINAL DOCUMENT

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MEADVILLE LOMBARD THEOLOGICAL SCHOOL, 2006

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ACKNOWLEDGEMENTS

Dr. Susann Pangerl, Director of the Doctor of Ministry program at Meadville Lombard Theological School, provided faithful guidance to me as I made my way through my doctoral studies. She served as the central advisor on this project, and was joined by Dr. John Tolley and Dr. Neil Gerdes as my faculty advisory committee. These advisors deserve much credit and gratitude for their time, advice and encouragement. Silvia Behrend, a doctoral student at Meadville Lombard, joined Dr. Pangerl and me for the Spring, 2005 Doctoral Seminar. Our conversations were essential to the development of this project. I would also like to thank Susan Byars, librarian for Hospice of the Bluegrass, for her assistance in the early stages of research for this project.

ABSTRACT

PALLIATIVE SPIRITUAL CARE: A MODEL OF MINISTRY WITH THE TERMINALLY ILL

BY

BONNIE JEAN MEYER

MEADVILLE LOMBARD THEOLOGICAL SCHOOL, 2006

This project is based upon the experience of eleven years as a hospice chaplain, the course work in the doctoral program, a review of related literature, and then, the writer's reflection upon on all of this. The model of ministry with the terminally ill which is proposed here draws from humanist and feminist streams of thought which encourage an empowering, along-side role of companionship for the minister. By companioning dying persons—hearing their stories and their struggles and responding with compassion—the minister is able to provide effective spiritual comfort.

INTRODUCTION

In his book, *The Dying* Soul, Mark Cobb bemoans the paucity of models of spiritual care for the dying. While acknowledging the problems inherent in trying to "capture aspects of care in simplified forms," he maintains that "in constructing models people are given the opportunity to share ideas and to debate and develop possibilities.[1] This project presents a model of spiritual care for the dying which focuses on the role of companionship. The goal in this model is spiritual comfort or relief from spiritual distress. This is a model of *palliative spiritual care.*

It is beyond the scope of this project to delineate a comprehensive counseling approach. Ministers may choose to utilize standard texts on counseling such as Gerard Egan's *The Skilled Helper*, now in its 7th edition.[2] It is also beyond the scope of this project to explain the basic skills of counseling, which are explained in standard texts such as William Cormier and Sherilyn Cormier's *Interviewing Strategies for Helpers*, now in its 4th edition.[3] Instead, this project provides a model for ministers to utilize in adapting their own basic counseling approaches and skills to fit the particular needs of persons who are dying.

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[1] Mark Cobb, *The Dying Soul: Spiritual Care at the End of Life* (Buckingham: Open University Press, 2001) 107.

[2] Gerard Egan, *The Skilled Helper: a Problem-Management and Opportunity-Development Approach to Helping,* 7th ed. (Pacific Grove, CA: Brooks/Cole, 2002).

[3] William H. Cormier and L. Sherilyn Cormier, *Interviewing Strategies For Helpers: Fundamental Skills and Cognitive Behavioral Interventions*, 2nd ed. (Montery, CA: Brooks/Cole, 1985). The second edition is referenced in this paper; there is now a 4th edition in print.

The first chapter explains the concept of palliative care in medicine, and then shows how palliative care applies to the psychosocial and spiritual care of the dying. Then, because pastoral counseling finds its basis in the disciplines of theology and psychology,[4] the second chapter examines these disciplines for guidance in palliative spiritual care. This model draws from the humanist shift of focus from supernatural to human agency, and from the feminist values of embodiment, interdependence, and vulnerability. The third chapter presents a metaphorical guide to help ministers achieve the alongside position and companioning role in their ministry with the terminally ill. Suggestions to help ministers put this model into practice are given in the fourth chapter. The fifth chapter offers a system of documentation which can provide a discipline as a minister strives to practice palliative spiritual care. Finally, the conclusion adds a note about the restorative benefit for ministers who utilize this model of care in their ministry with the dying.

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[4] Browning describes pastoral counseling as "a synthesis of two important cultural resources—the Judeo-Christian tradition and the modern psychologies." Donald Browning, "Introduction to Pastoral Counseling," in *Clinical Handbook of Pastoral Counseling, Vol. 1,* expanded ed., eds. Robert J. Wicks, Richard D. Parsons, Donald Capps (Mahwah, NJ: Paulist Press, 1993) 12.

1. PALLIATIVE SPIRITUAL CARE

Palliative Care

Hospices have defined a niche for themselves within medical care: hospices provide care for those who are terminally ill and who choose to receive care which focuses on *comfort*, having abandoned efforts for *cure* which have become futile. Care which focuses on comfort and the relief of suffering is called "palliative care."[5]

Some people wonder how anyone can work with the terminally ill on a daily basis. The work is satisfying because hospice efforts to help those who are dying to find comfort are usually successful. The key is in clarifying the goal of the care as *palliative* care. Were hospice employees to try to find cures for their patients' illnesses, they and their patients would experience frustration and failure. But that is not the goal. The goal is to provide comfort, and this goal is usually attainable, thanks to some great medicines available for pain, anxiety, nausea, shortness of breath, etc.

Social workers, chaplains, and counselors do not use medicine, yet they too work within the hospice purpose of providing *palliative* care. Indeed, Barry Kinzbrunner claims that the interdisciplinary nature of hospice care is part of what makes it palliative care.[6] As the study of care for the terminally ill exploded in the 1970s, coinciding with

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[5] Palliative care extends beyond hospice care. Palliative care specialists address the issues of pain and suffering throughout medical practice. Hospices retain the niche in providing palliative care for the terminally ill.

[6] Barry M. Kinzbrunner, "Palliative Care Perspectives," in *Palliative Practices: an Interdisciplinary Approach,* eds. Kim K. Kuebler, Mellar P. Davis, and Crystal D. Moore (St. Louis: Mosby, 2005) 6.

the introduction of the hospice movement, Edwin Shneidman proposed twelve rules for counseling the terminally ill. The very first rule is that the goals are different: "the omnipresent goal is the psychological *comfort* of the person . . . [emphasis his]."[7]

Valerie Young notes that "Counseling dying or grieving people is a specialized part of therapy. It involves different goals and often uses a different process of interaction."[8] She claims that it is a time for healing, not for uncovering work. She goes on to list several descriptions of the goal: providing support and comfort, resolution of fear and guilt, and self-actualization and a deeper understanding of the universe. In the care of dying people, the goal of all aspects of the care shifts to that of comfort.

Chasing the Wind

One hospice patient, "Tony," taught me the first lesson one must learn in order to provide palliative spiritual care. He was talking about his brother who had just walked out of a drug rehabilitation program, dashing Tony's hopes that his brother would free himself from his addiction. Tony told me that a person's first experience with "crack" cocaine can be exhilarating, with the effect that the person then keeps trying to repeat that experience, yet is never able to do so. Tony then said the words that taught me the lesson: "It's like chasing the wind." I reflected on Tony's words for a long time, realizing that in many ways we all "chase the wind" in our lives, striving for something that is just not going to happen.

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[7] Edwin S. Shneidman, "Some Aspects of Psychotherapy with Dying Persons," in *Psychosocial Care of the Dying Patient*, ed. Charles A. Garfield (New York, NY: McGraw-Hill, 1978) 210.

[8] Valerie Young, *Working With the Dying and Grieving* (Davis, CA: International Dialogue Press, 1984) 22.

To have a goal of physical cure when cure is not possible is to chase the wind. To have a spiritual goal of cure (i.e. to finally see oneself or a loved one become a different and more acceptable person or to finally realize life goals which have previously proven elusive), *when these things are not possible*, is to chase the wind. It is better to stop chasing the wind, just stop, and let the wind bring to us what *is* possible. It is when we stop, through the process of letting go, that transformation occurs and comfort is found. There is a time to fight for cure, but when the fight has become futile, it is time to let go.

When a person has let go of that fight for cure, those around them (doctors, family, friends, and clergy) must also let go, in order to journey with the person rather than leaving the person to journey alone. Stephen Levine sums it up in these words:

> If someone is dying and those around them insist that they do not die, the person dies in isolation, alone and without the love that can offer such support and such a sense of completion . . . . Truly, you can't go through the door with her, but you can accompany her more fully to the threshold.[9]

J. William Worden, in his foreword to Rando's *Grief, Dying, and Death*, notes:

> In 1974 Elisabeth Ross and I asked 6,000 health care providers if working with the dying presented any difficulties for them. Of the 98% who experienced difficulty, many said it was because the dying patient confronted them with their own mortality. I believe this same phenomena exists today. To develop skills in terminal illness care without addressing the issue of personal death awareness is to miss an important dimension . . . .[10]

It is through coming to an acceptance of the limits in one's life, and most basically the limit imposed by one's own inevitable death, that one learns to stop "chasing the wind." As a minister develops the ability to let go in her own life she is able to be fully present with others through the myriad of "letting goes" that accompany the process of dying.

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[9] Stephen Levine, as quoted in Gail Perry and Jill Perry, *A Rumor of Angels: Quotations for Living, Dying, and Letting Go* (New York: Ballantine Books, 1989) 34.

[10] Therese A. Rando, *Grief, Dying, and Death: Clinical Interventions for Caregivers* (Champaign, IL: Research Press, 1984) vii.

2. THEOLOGICAL SOURCES FOR PALLIATIVE SPIRITUAL CARE

Two relatively recent streams within Western theologies are particularly helpful in the development of a theoretical foundation for palliative spiritual care: humanism and feminism. Humanism moves ministry away from the traditional focus on supernatural agency (and human sin) to a focus on human agency, and encourages a person-centered approach to counseling. The tendency towards coldness and detachment in ministry which was informed by "old" humanism is corrected through the feminist values of embodiment, interdependence and vulnerability.

The Humanist Influence

Humanism and Theology

William Jones notes that "there are two basic religious traditions in Western thought: a mainstream tradition of Christian and non-Christian theism, and a minority tradition of humanism."[11] Jones goes on to argue that "the central affirmation of humanism, the *functional* ultimacy of the human being—i.e., the radical freedom and autonomy of humankind—is materially a formative category of contemporary theology [emphasis his]."[12]

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[11] William R. Jones, "Theism and Religious Humanism: The Chasm Narrows," *The Christian Century* (May 21, 1975: 520-525) 520.

[12] Ibid.

Bill Murry adopts Jones' affirmation and then clarifies that there is not a great deal of difference between naturalistic theists and religious humanists, in that both affirm "the dignity and worth of each person, the importance of reason and evidence in making judgments, dedication to the well-being of all people, and an affirmation of the authority of *human* experience [emphasis his]."[13] A key difference then, between what Jones calls the mainstream theistic tradition and what he calls the minority tradition of humanism (to which Murry includes naturalistic theists) is the difference in the value given to human agency. The mainstream theistic tradition tends to devalue human agency through an emphasis on supernatural agency in its assessment of "ultimacy," whereas the minority humanist tradition values human experience and human agency.

What this implies for ministry with the dying is a difference in the position of the minister vis-à-vis the dying person.[14] The mainstream theistic tradition emphasizes the agency of a supernatural deity, and places the minister in a mediating position between the supernatural divine and the dying person, by implication, detached from and above the dying person. The attention often is less on the experience of the dying person, and more on the hope of supernatural intervention either in this life or in an afterlife.

The humanist or naturalistic theistic view, through a focus on and valuing of the human experience of the dying person, provides support for an alongside position, from which the minister can interact in a way that respects that person's experience. Naturalistic theists and religious humanists are thus able to embrace the human struggle

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[13] William Murry, "Religious Humanism Yesterday, Today, and Tomorrow," *Religious Humanism* 34, no 3&4 (Summer/Fall 2000: 55-90) 76.

[14] The use of the phrase, "the dying person," is admittedly awkward and impersonal. The terms "client" or "patient" would be less awkward and more personal; however, these terms are not generally used in reference to persons that a minister visits.

with issues and feelings of grief and loss, the human struggle to adapt to the changes in one's life.

It is important to note than many ministers from the traditional theistic tradition are also willing to utilize the companionship role and the alongside position in their ministry. Some draw support for this position from minority strands in their theology,[15] while others draw support for this position from psychology.[16] This leads us to consider how psychology too has been impacted by humanism.

Humanism and Psychology

Humanism in the early twentieth century began to impact the field of psychology through the work of Carl Rogers and Abraham Maslow.[17] In contrast with the prevailing practice of psychology of the time, humanistic psychology gave greater credence to the client's self-understanding, and gave more attention to positive growth rather than focusing primarily on pathology. This led to a client-centered, or more recently, to a person-centered approach to counseling. Humanism impacted the understanding of the role of the therapist, bringing the therapist from a position of "authority over" towards a

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[15] Wayne E. Oates, *Grief, Transition, and Loss: A Pastor's Practical Guide* (Minneapolis: Fortress Press, 1997). Oates uses Isaiah 53:3 to portray the role of clergy as fellow sufferers with those who suffer.

[16] Ian Ainsworth-Smith, *Letting Go: Caring For the Dying and the Bereaved* (London: SPCK, 1982). In the Forward the series editor, Derek Blows, states that pastoral care draws from the secular helping professions. In the Introduction, Ainsworth-Smith states that the authors draw from extensive psychological studies.

See also Gerald Calhoun, *Pastoral Companionship: Ministry with Seriously Ill Persons and Their Families* (New York/Mahwah: Paulist Press, 1986). Calhoun bases the role of companionship upon his reflections on his experience with patients and families at Youville Hospital and listening to other chaplains in similar settings.

[17] Carl Rogers, *On Becoming a Person: a Therapist's View of Psychotherapy* (NY: Houghton Mifflin, Copyright 1961, Introduction copyright, 1995). A new introduction by Peter Kramer points to the significance of Carl Rogers' work in humanistic psychology, particularly his "client-centered" approach.

position which gave more value to the experience of the client (the client's self-understanding and the client's goals).

Companionship. Gerard Egan portrays the counseling relationship as a "working alliance." He states, "helpers and clients are collaborators. Helping is not something that helpers do to clients; rather, it is a process that helpers and clients work through together."[18] This model proposed here modifies Egan's approach by portraying the relationship as one of companionship more than that of collaboration. This modification reflects the shift in the goals of the counseling from that of helping people make changes and solve problems in their lives, to a goal of providing comfort and support in the dying process.

Alan Wolfelt,[19] a noted Christian grief educator, utilizes the companion model in his approach to bereavement counseling. He spells out his understanding of companioning with these statements:

- Companioning is about honoring the spirit; it is not about focusing on the intellect.
- Companioning is about curiosity; it is not about expertise.
- Companioning is about learning from others; it is not about teaching them.
- Companioning is about walking alongside; it is not about leading.
- Companioning is about being still; it is not about frantic movement forward.
- Companioning is about discovering the gifts of sacred silence; it is not about filling every painful moment with words.
- Companioning is about listening with the heart; it is not about analyzing with the head.
- Companioning is about bearing witness to the struggles of others; it is not about directing those struggles.
- Companioning is about being present to another person's pain; it is not about taking away the pain.
- Companioning is about respecting disorder and confusion; it is not about imposing order and logic.

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[18] Egan, *The Skilled Helper*, 43.

[19] Alan Wolfelt, "Companioning vs Treating: Beyond the Medical Model of Bereavement Caregiving—Part 3." *The Forum Newsletter*, Association of Death Education and Counseling, (Nov/Dec 1998).

- Companioning is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.

Drawing from his experience as a hospice counselor, Greg Yoder uses Wolfelt's list of tenets on companionship as a basis for his book, *Companioning the Dying*. Yoder seeks to help the caregiver to "bring a respectful, nonjudgmental presence to a dying person."[20]

The model of palliative spiritual care presented here takes this key concept from the stream of humanism as it has impacted Western theology and psychology: the value given to human agency and human experience, and the corresponding shift to an alongside, person-centered, companioning approach to counseling and ministry.

The Feminist Influence

Embodiment, Interdependence, and Vulnerability

The second stream, feminism, makes essential adjustments to the stream of humanism (in addition to its primary criticism of the patriarchal nature of traditional Western theologies and psychologies, which will receive further comment later in this chapter). Rebecca Parker summarizes three ways that the women's movement has challenged our understanding of what it is to be human: by arguing for the significance of embodiment, of human interdependence, and of vulnerability.[21] In response to the emphasis in early twentieth century, or "old," humanism on rationalism and the life of the

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[20] Greg Yoder, *Companioning the Dying: A Soulful Guide for Caregivers* (Fort Collins, CO: Companion Press, 2005) 5.

[21] Rebecca Parker, "Vulnerable and Powerful: Humanism from a Feminist Perspective," *Religious Humanism* 27, no.2 (Spring 1993) 55-66.

mind, feminism reminds us that our minds exist only in bodies, and that we live in the world. Feminism also presses the notion that we are interdependent and interconnected with all of life, in contrast to old humanism's tendency to stress our separateness as individuals. In response to old humanism's value of toughness and impermeability to pain, Parker notes: "The women's movement has pushed against this myth of human being by insisting on making public—breaking silence, telling the truth about—how deeply vulnerable we, in fact, are."[22]

Parker then applies these ideas to theological views of suffering, and is highly critical of the dominant "religious mythos that says the silencing of suffering is right [and] views suffering as holy, sacred, and life giving."[23] When suffering is to be silenced, with both the suffering and the silence valued, those who are suffering find little comfort. I once heard a minister tell the parents of a sixteen-year-old who was killed in an automobile accident that they were not to be angry at God in this situation. The minister did not have a primary goal of comforting the parents; his goal was likely to reassure them of their religious beliefs about God.

Embodiment, human interdependence and vulnerability: these values are essential for palliative spiritual care. Embodiment means that the dying that is happening to the body cannot be disconnected from the emotional and spiritual experience; the minister helps the person to integrate the whole rather than encouraging a denial of the emotional or spiritual aspects of the process of declining health and dying. Acceptance of human interdependence, in palliative spiritual care, means that the minister is positioned alongside the dying person, and that the relationship is characterized by

[22] Ibid., 60.

[23] Ibid., 63.

mutuality, companionship, and empowerment. Acceptance of vulnerability means that the minister recognizes and comes to terms with her own vulnerability (especially in terms of her own mortality), and thus is able to companion those who are dying.

Non-Hierarchical Relationships

Beyond these three values through which feminism corrects old humanism, feminism's criticism of patriarchy provides a correction to Western theologies. Feminist writers have effectively shown how patriarchy, through its hierarchal rendering of relationships which place men over women, clergy over laity, etc., denigrates the value of women's lives. The artificial limitations inherent in patriarchy also diminish the lives of men. Feminism instead presses for relationships characterized by mutuality and interdependence, and for a non-hierarchical understanding of the ministerial relationship.

Incorporating these influences, this model calls for the alongside, companioning, and empowering position of the minister while providing palliative spiritual care. Instead of instructing the parents not to be angry at God, the minister noted above would have asked the parents how this tragedy was affecting them and offered to be supportive of them during this difficult time, and then listened as they poured out their grief and anger, thereby helping them to find comfort and relief from suffering.

Humanism and Feminism in the Theory Of Palliative Spiritual Care

The awareness of the value of hearing the voices and valuing the experience is seen in Elisabeth Kubler-Ross' ground-breaking work, "*On Death and Dying: What the*

Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families."[24] Her theory is based upon what she heard from people who were dying. Judith Viorst, in her classic work on the developmental potential in the losses in our lives, notes that Kubler-Ross "describes the enormous relief provided to dying patients when they are invited to share their fears and their needs . . . and argues that such dialogues can ease their journey toward death . . . ."[25]

John Harvey provides some sense of how and why these "dialogues" help, in his social psychological view of human as storyteller: "As people share their stories with others, they name and shape the meanings of their unique life experience."[26] He notes that the telling of stories can influence the teller in profound ways, including the venting or releasing of emotions and the clarifying of thinking. Harvey asserts that the telling of stories, or "account-making," has great value in dealing with the major stressors in life.

Therese Rando notes: "counseling the dying patient is the most nondirective form of assistance there can be," and adds: "therapeutic communication expresses respect for the patient, maintains realistic hope, and offers appropriate reassurance and support."[27]

These writers provide support for a theory of ministry with the dying which calls for the minister to provide companionship in a way that draws out and responds to the stories, the emotional struggles, and the deepest cry in the hearts of those who are dying.

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[24] Elisabeth Kubler-Ross, *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families* (New York: Collier Books, 1969).

[25] Judith Viorst, *Necessary Losses: the Loves, Illusions, Dependencies and Impossible Expectations That All of Us Have to Give Up in Order to Grow* (New York: Simon and Schuster, 1986) 310.

[26] John H. Harvey, *Give Sorrow Words: Perspectives on Loss and Trauma* (Philadelphia: Hove: Brunner/Mazel, 2000) 26.

[27] Rando, *Grief, Dying, and Death*, 282.

Respecting the Values and Beliefs Of Those Who are Dying

Palliative spiritual care is given in a manner which understands the great diversity among patients and families, and respects the values and beliefs of the patient and their family. It is not the minister's purpose to tell those who are dying what they must do and how they must live out their final days, as the minister does in the movie *The Sea Inside*.[28] This minister, himself a quadriplegic, tries to impose his own experience and theology upon Ramón, in an attempt to stop Ramón in his efforts to win the right to death with dignity. The minister adds to Ramón's distress rather than bringing comfort.

It must be noted that palliative care does not mean passive care. In hospice literature palliative care has sometimes been mistakenly contrasted with aggressive care, leaving one to possibly conclude that palliative care is in some way the opposite of aggressive. This is false. Palliative care includes intense treatment. The difference is in the goal, as noted previously. Palliative care includes aggressive, intense symptom control rather than aggressive attempts to cure the disease. In the same way, palliative spiritual care does not infer passive care or mere passive presence. The minister hears and responds in an active interchange which is directed towards a goal of spiritual comfort.

This goal is achieved, not by imposing arbitrary authority, but by offering one's experience and expertise in spiritual care for consideration. The dying person is free to accept or reject the guidance of the minister, with the assurance—and this is key in this model—that the minister will continue to provide companionship. The minister in the movie *The Sea Inside*, failed to continue in companionship when Ramón rejected his

[28] *The Sea Inside*, 125 min., foreign with English subtitles, (USA: Fine Line Features, December 17, 2004).

counsel. This model requires the minister, when offering challenge or guidance, to do so in a manner that respects the values and beliefs of those who are dying, and therefore allows the minister to continue in companionship with those who choose a path other than the minister's preferred path.

One woman in her 30s with four young children was unable to make use of a free family trip to Disney World, because she (under the direction of her minister) was afraid that taking the trip would be an admission that she was dying. She was instructed to hold on to a hope for divine intervention. As a result, she lost the opportunity to make the most of her final months with her husband and children, and to take a trip which could have provided lasting memories for the children. If the minister had instead offered his guidance in a way which allowed her to disagree with him without losing his support, he would have heard what she was telling others, that she knew she was dying and wanted to take this meaning-making trip with her family. His response then would be to "bless" the trip, thereby empowering her and continuing in companionship with her.

The Transformation That is Possible

Some ministers might not impose such a strong expectation for a supernatural healing of physical ailments, but perhaps create the expectation for a "conversion" which does not respect the dying person's own sense of a need for such a change. Someone else imposes the need for a change: a relative, a friend, or perhaps a minister. People then are encouraged to "hold out" for the change (even if there is every reason to believe that this is a futile hope). Lost is the opportunity for companionship and support in the journey towards acceptance and letting go. Human beings are certainly capable of

transformation, but a goal of change which is imposed by others upon the one who is dying is very unlikely to take place (except perhaps superficially in an attempt to please the other).

This is also true of changes which the dying person wishes to impose on others. I have met many dying parents who are still waiting in vain for their adult son or daughter to become the son or daughter they want them to be. They are therefore unable to appreciate or enjoy the son or daughter as they are (which would be the transformation most likely to be possible, that is, the parent letting go of the wish for change in the son or daughter). The dying person and their families then miss the opportunity to find what resolution is possible, as they continue to "chase the wind."

The minister who has embraced the concept of palliative spiritual care is able to respectfully challenge the imposition of futile goals, and to encourage the dying person and those around them to set goals which are attainable. The minister then continues to provide companionship in the direction chosen by the dying person.

The Minister as Companion

By reminding us to attend to that which is humanly possible, to respect each person's voice and experience, and to value embodiment, interdependence, and vulnerability, humanism and feminism encourage clergy to minister as companions, alongside those who are dying. For the dying, comfort comes as they find companionship and support in their own particular processes of grieving and of letting go, and when they are then able to fully celebrate what can be celebrated.

3. METAPHORICAL GUIDES FOR PALLIATIVE SPIRITUAL CARE

To provide palliative spiritual care in a manner which values human agency, embodiment, interdependence and vulnerability requires most fundamentally the ability to find a place alongside the dying person, in order to join the dying person as a temporary companion in his or her journey. How then does one practice ministry, with a wide diversity of people, in a way that routinely finds this place? The language of metaphor can serve as a guide for the minister in assessing where a person is, emotionally and spiritually, and then in finding a place alongside.

Beside the Big Lake

The first metaphorical place where a person may "be" during a visit is "beside the big lake." I draw this image from visits my family made to Lake Michigan during my childhood. Since this lake was less than a mile from our home we spent many hot summer afternoons on the beach. We called Lake Michigan the "big lake," to contrast it with the numerous small lakes in Michigan.

I remember the big lake as being a place of distraction. On the one hand, going to the lake was a distraction from work for our parents. On the other hand, it was impossible to have much of a conversation with anyone at the lake due to all of the distractions present: the noise of the wind and the waves, children screaming, and a wide variety of beach activities taking place.

Often a whole visit, or a part of a visit, can be visualized as a visit taking place beside the big lake. There are a lot of distractions present, and the conversation stays focused on the various distractions: the television may be on during the visit, or the attention may jump from the weather outdoors to what a person nearby is doing or how the local baseball team looks this year.

Ministers often refer to these visits as visits that remain on a social level. The conversation stays on a surface level, never getting to any deeper thoughts and feelings. During these times the minister can picture the person that she is visiting as if he were sitting on the beach beside the big lake, and then picture herself dropping down to sit beside him on the sand so that they can comment together on the distractions. This puts the minister in the alongside position, where there is the greatest likelihood that she will hear whatever the dying person may try to say.

Companionship Beside the Big Lake

The effective response of the minister, in order to provide comfort, begins by fully joining the dying person beside the big lake. It can be comforting simply to have companionship, even if the conversation stays on a social level. It is important, however, that the minister not become so entranced by the distractions that he misses indications that the other person is ready to move to another, deeper, space. The minister must not become the source of distraction! It may be here, beside the big lake, that the dying person is assessing whether the minister would be helpful at a deeper level, and much of that depends on whether the minister catches the cues to move deeper levels.

Everyone needs times of distraction in life. The minister should not automatically make the assessment that the dying person is resisting dealing with deeper issues or is "in denial." She may simply be in need of respite. Shneidman writes: "It is only human even for the most extraordinary being occasionally to blot out or take a vacation from his knowledge of his imminent end. It is probably psychologically necessary for the dying person intermittently to rest his own death-filled train of thoughts . . . ."[29] The role of the minister is to recognize the place where the person is at and to join her there, with the goal of helping her find whatever comfort is needed and wanted. Although the comfort provided at this level may be correspondingly shallow, this experience of companionship and comfort has the potential to lead to other, deeper places. An attentive minister, moreover, is likely to notice subtle messages hinting at places of pain. In any case, finding companionship "beside the big lake" might be just the sort of comfort that this person needs and wants at this time.

Beside the Busy Creek

The second metaphorical place where the minister may find a dying person during a visit is "beside the busy creek." Near my childhood home there was a creek that wound its way back and forth across our neighbors' properties, crossing under the road at two places where we loved to play. There was "busyness" about the creek: it was always doing something and going somewhere. We were busy when we played by the creek: catching frogs, butterflies, and water spiders, and building simple boats that would be carried away down the stream.

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[29] Shneidman, "Some Aspects of Psychotherapy with Dying Persons," 212.

Visits or parts of visits with terminally ill people can sometimes be seen as taking place beside the busy creek. These are the times when people are processing or working through the thoughts and feelings and issues in this final portion of their lives. They may engage in "life review," telling stories from their lives. They may tell the stories of the loss of their health, as they struggle to integrate this reality into their life stories. This may be understood as "finishing their business." Harvey calls this process "account-making" and sees its value in providing some sense of meaning, and thus a sense of a bit of control, in one's life.[30]

Diane Rooks[31] provides an exploration of the potential healing from this sort of account-making, describing how stories do the following:

- open hearts and teach us to grieve
- render meaning from chaos
- penetrate barriers with images
- preserve and perpetuate memories
- validate listeners as individuals
- connect us to the universe
- expand imagination and creativity
- enable growth and learning
- transform pain
- establish control and closure
- restore the future
- offer hope

Companionship Beside the Busy Creek

When the minister observes that this is where a person is, metaphorically, during a visit, she can picture herself with him beside the busy creek. While there, the minister

[30] Harvey, *Give Sorrow Words*, 27.

[31] Diane Rooks, *Spinning Gold Out of Straw: How Stories Heal* (St. Augustine, FL: Salt Run Press, 2001). Rooks devotes a chapter to each of these potential benefits of stories.

listens to the stories with compassion. Indeed, the minister listens in such a way as to draw out the stories and thereby assist in their formation. The minister, in the words of Silvia Behrend, "enables the remembrance of a lived life, serving both as midwife and as witness."[32]

The dying person may be building little boats ("account-making") consisting of the parts of his life which he is letting go in the creek. Some of the boats are cast off with a sense of pride and accomplishment, while others are sent away in resignation, accepting realities in his life, things that never will become what was wanted or hoped for. In some cases the person is expressive of anger and frustration and seems to fight with the boat rather than sending it down the stream. The minister is there to witness and honor ("bless") the letting go of each boat, or even the struggle which finds no resolution. The person often finds meaning, validation, empowerment and comfort in this process.

Beside the Still Waters

There is a third metaphorical place where the minister can visualize visits, or parts of visits, taking place: "beside the still waters." One day as a teenager I walked further down the beach than usual, and I discovered the place where the creek empties out into Lake Michigan. I followed it back between two small sand dunes and found that the creek widened into a pool of water just before the end of its journey to the lake.

Though the creek moved through this pool its movement could not be seen; the surface of the pool was still. I sat on the side of the sand dune and marveled at this unexpected sight. I could see trees that had fallen into the pool, along with assorted items

[32] Silvia Behrend, statement made as part of conversations during the Spring, 2005 Doctoral Seminar, Meadville Lombard Theological School.

of trash. The spot invited a reflective mood. The surface of the pool was the first thing noticed, but things beneath the surface were clearly revealed.

Beside the still waters, in a place that is reflective and where the deepest and most intimate truths are revealed, is the third place that the minister can visualize in assessing where the dying person is, emotionally and spiritually, at times during visits. These are the moments when the person reveals the places of his deepest feeling, sensitivity, and vulnerability. This is the place of confession, not primarily confession of wrongdoing (although sometimes this is the case), but confession of one's deepest truths as one reflects upon a life lived.

Companionship Beside the Still Waters

The minister often provides comfort here through silent witness and non-verbal signs of affirmation. Words if spoken must be carefully chosen lest they prematurely end the intimacy of the moment, or worse, lest they add to the pain of the dying person, either by minimizing his experience or by proposing a solution (which is usually not desired at this time). The minister may reflect what is heard, gently, for clarification and to let the dying person know that he was heard. Non-verbal communications of compassion and kindness, which also let him know that he has truly been heard, provide much comfort.

William and Sherilyn Cormier elaborate on listening responses, and state: "we consider listening responses to be the foundation of the entire counseling process." They continue, "clients will usually feel listened to and understood most when you let them know you have seen things from their frame of reference, heard what they have said, and

felt or grasped their feelings and experiences."[33] For assistance in developing effective listening responses, ministers can refer to the Cormiers' textbook.

Moving Among the Metaphors

The dying person will often move from one metaphorical place to another during the course of any visit. The entry to the still waters may be a very quiet comment. If the minister is not paying close attention, the entry may be missed as the minister continues in another sort of space and the dying person then misses the "listening response" needed to continue in the more intimate space and instead rejoins the minister beside the busy creek or beside the big lake.

The minister must maintain awareness of his or her own power to control where the visit takes place in terms of these metaphors. An invitation may be extended to move to another space if offered in such a way that the person is free to accept or reject the invitation, with the assurance that the companionship will continue. The minister accompanies the other while maintaining a readiness and openness to move to a different sort of space at any time. In this way, the minister is able to position herself alongside the dying person, the position essential to palliative spiritual care.

[33] Cormier and Cormier, *Interviewing Strategies for Helpers*, 90.

4. SUGGESTIONS FOR THE PRACTICE OF PALLIATIVE SPIRITUAL CARE

One day I entered a nursing home to visit a very feeble woman who had been receiving hospice care for several months. As I approached her bedside and greeted her, she invited me to take a seat. Since her wheelchair was the only chair in the room, she indicated that I could sit there. I noticed a blue pad on the chair but everything looked fine so I sat. It took only a few seconds for me to feel the wetness from the pad soaking into my pants, and there was no doubt in my mind about what that wetness was. I quickly ended the visit and departed.

This very brief visit shows some things about a visit which follows this palliative spiritual care model and demonstrates the values of embodiment, interdependence, and vulnerability. The feeble woman and I both had needs, needs stemming from the fact that we live in bodies. I needed a place to sit. She attempted to help me meet that need. I was vulnerable in that, after my pants too became wet, I shared in her sense of a loss of dignity due to her inability to control her bladder.

The visit also demonstrates what happens all too often when a minister is impacted by the suffering of those who are dying: a hasty departure! In most cases, however, the departure is due to an emotional need rather than a physical need. To remain fully present with those who are dying requires the emotional ability to resist the urge to get away from painful situations that may have no remedy.

This chapter contains ten suggestions for ministers to consider in their ministry with the dying, based on things that I have learned as I have applied this model of palliative spiritual care. These suggestions will help the minister to find that place of companionship and support alongside those who are dying, and to stay there through the difficult moments, and thus to help them find comfort. These suggestions are intended to help the minister adapt her basic counseling approach and skills to the needs of the dying, and therefore assume basic knowledge and skills in pastoral counseling.

Before the Visit

Suggestion #1: Prepare For Companionship

Prior to the visit, it is important for the minister to remind herself of the dying person's name, and any key information that she would be expected to know. If she has documented prior visits she can review her notes. It is easy to forget important things that people tell us, and their assessment of our abilities as ministers will suffer if we blunder in this manner. On the other hand, showing evidence that we heard what was said in prior visits demonstrates that we care about and respect the person we are visiting. Preparation is the first step towards companionship with the dying.

Suggestion #2: Connect in a Way That Shows Mutuality

Making a "considerate" connection is the second step. Upon arrival, the minister can begin by asking if this is a good time for a visit (even if the time was prearranged). This shows respect for the other person's needs, and is a move towards companionship

and an "alongside" position rather than a position of superiority. This is a way for the minister to take into consideration the physical needs of the dying person, thus demonstrating the values of embodiment and vulnerability. There are often times when a dying person may be too ill for a visit, yet may be reluctant to put his needs over those of the minister. By asking the question, the minister empowers him to speak up for his needs.

I usually say something like this: "Hi Mr. Smith, it's Bonnie Meyer, the chaplain from hospice. Is this a good time for me to visit you?" Saying who I am (if there is any possibility that the person may struggle to remember my name) is a way, once again, to share power and to begin to establish a place alongside.

During the Visit

Suggestion #3: Sit Down

The visit itself, in this palliative model, requires the minister to physically sit down. This may seem obvious, but when I ask dying people if their minister visits, the answer too often includes the qualifier, "but she did not sit down." There seems to be an understanding that a visitor who does not sit down is not staying long and that this will be a superficial visit. Instead of what may be a common offer in some clergy visits, "May I say a prayer?" ministers can say, "May I take a chair?" Even if the visit only lasts ten or fifteen minutes, due to the needs of either the minister or the person visited, it will take on a different character if the minister sits. Standing not only reflects a superficial visit, but it also reflects a position of power-over. Sitting demonstrates the more supportive, companioning role needed for palliative spiritual care.

Suggestion #4: Listen

The minister needs to have good skills in communication. In order to effectively help someone find comfort the minister must be able to discover, through communication, what needs comforting. Furthermore, in the case of the dying, who may not have the time to change or eliminate the sources of their spiritual distress, the only comfort they may find is the comfort in telling the minister about it, and feeling that they have been heard and understood. The minister, by listening, bears witness to the points of regret and anguish, as well as bearing witness to the points of gratitude or celebration.

This of course requires that the dying person talks! If the visit was made at the request of the dying person, the talking will usually follow as the minister asks if the person had a particular reason for the visit request. If the visit was made on the initiative of the minister, it falls on the minister to provide the reason for the visit. After introductory greetings and remarks, the minister may say something like this: "I am here to talk with you about how you are doing, and to give you someone to talk to, if you would like." This sends the message that the dying person has choice about talking to the minister. The minister may add something like this, "We don't have to talk about deep matters, there doesn't need to be some sort of crisis, we can talk about the weather (!), but if there are deeper issues, we can talk about them." This sends the message that the minister is here for more than superficial chitchat, if more serious conversation is needed and wanted. The minister may also add, "Sometimes just talking about things, even if there is no solution, helps." This comment lets the person know that the minister will accept reality as the dying person experiences it, and will not impose an unwanted, superficial solution.

If the person indicates that they are open to conversation, the minister can invite the person to engage in life review, or story-telling, by a simple question such as, "When did you first know that you were seriously ill?" Asking about any point in a person's life gives her an entry point to then tell other parts of her story if she wishes to do so.

Suggestion #5: Observe Metaphorical Places, Painful Places, and Joyful Places

Throughout the visit, the minister actively listens, fully engaged with what is being said. At the same time, the minister observes and mentally notes which of the three metaphorical places the person is in, so that when she moves to another place the minister is able to move with her. This enables the minister to serve as companion in the alongside position. The listening minister also mentally notes issues that seem to be causing the dying person spiritual distress, as well as causes for celebration. This informs the minister as to the areas where comfort and relief are most needed.

One man that I visited, whom I will refer to as "Henry," in our second meeting, spent most of the visit time telling me about a supervisor who treated him poorly during the fifteen year period that they worked at the same school. It became clear to me that this wound had not healed in the twenty years since Henry had retired. Wounds, grudges, grief, regret, and other sources of spiritual pain will come to the surface if a person chooses to talk openly with the minister about his life.

Suggestion #6: Respond With Compassion

This brings us to the sixth thing that the minister must do: respond. As a companion the minister must engage the other in dialogue. Palliative spiritual care is not

merely passive presence. Initially, the minister's part of the conversation may be statements which demonstrate that he is listening, and inviting the dying person to go on with his story. As the visit continues the minister gives "listening responses" that clarify and affirm what is heard, words that validate the experience, words that demonstrate compassion, and sometimes, words that challenge or offer guidance that respects the values and experience of the one who is visited. Challenges, in this model, are offered in a way that allow the companionship to continue even if the dying person rejects the challenge. Challenges too are ruled by compassion.

After hearing about Henry's experience with his supervisor, the minister could initially respond by saying, with compassion, "your experiences in relationship to that supervisor have caused you a lot of anguish." This response would indicate what the minister has heard, and thereby provide a way of checking out whether the minister's assessment is correct. This response also reflects to Henry a source of spiritual distress which he may have previously underestimated. The minister could then ask Henry if he would like to "re-consider" (consider in a new way) his relationship with the supervisor, with the goal of finding relief from this anguish. Confrontation or challenge, in this model, is not done arbitrarily from a position of "authority over." Instead, confrontation takes the form of a respectful and compassionate offering of another perspective. This perspective is not presented as if it was the only right perspective; it is open for further dialogue, and it never rules out continued companionship.

Suggestion #7: Avoid Three Common Response Errors

The minister must avoid three faulty "listening responses" which are unfortunately common for clergy. First, the minister must avoid giving responses which minimize or deny the suffering which the person is expressing or experiencing. These include remarks such as, "things could be worse: look at Mr. Jones over there," or, "we just need to focus on the things we are thankful for."

Second, the minister must avoid making such long responses that she dominates the conversation, mistaking the bedside of an ill person for a pulpit. After visiting numerous dying people, it is clear to me that very few people appreciate mini-sermons at their bed-side, whereas almost everyone appreciates a compassionate listener.

Third, the minister must avoid to making a comment which is experienced by the person as "blaming the victim." For example, the minister may believe that Henry might find relief by working towards finding a less painful way to look at the supervisor's actions towards him, through reframing, letting go, or by somehow coming to accept the supervisor's human limitations. This implies that Henry needs to make an internal change. If the minister chooses to offer this perspective for Henry's consideration, it must be done in a way that does not seem to Henry to exonerate his supervisor and blame him (for simply having the "wrong" perspective all of these years), in which case Henry would not feel understood by the minister.

Most of these sorts of response errors can be avoided if the minister is in the alongside position, companioning the dying person. Joining the person where they are gets the minister in touch with how the person is thinking and feeling; this helps the

minister to hear and to understand. If the minister truly does hear and understand, she is more likely to respond in a way that leaves the dying person feeling heard and understood. Also, by embracing a goal of comfort rather than cure, the minister will be able to stay with the person in the place of pain rather than quickly moving to try to point a way out of the pain. Where cure may imply the application of a treatment from a detached position, comfort implies hearing and being with the one who is hurting.

Ending the Visit

Suggestion #8: Find a Comforting Closure

As the visit is drawing to an end, the minister and the dying person can often find comforting closure through re-touching what was said and heard during the visit. If the dying person is accustomed to some sort of liturgical function this is a good use for that function. In this way the liturgical function serves to validate what the dying person has said, rather than to deny or minimize it. A reading, a prayer, a song, or a ritual which touches and values what has been said demonstrates that the person has been heard, and also presents this to God or to the spirit of life or to whatever is felt by the person to form a connection to a greater whole. This must be done in a respectful manner so that the minister does not leave the person feeling that their vulnerability remains uncomfortably exposed.

During the closure, the minister can once again help the dying person find a sense of validation and normalization for her experience. If the point of pain was loneliness, the minister might say something like this towards the end of the visit: "loneliness is something that so many people suffer when their health begins to fail and they become

more isolated in their home or nursing home." Unless it is clear that a solution is both desired and possible, the minister must take care not to go on to give her a suggestion for reducing her loneliness! That would be an attempt at cure rather than comfort, and the person likely knows that her loneliness, at this point in her life, cannot be cured, so she would know that the minister does not understand.

As long as the purpose is to demonstrate a validation or blessing of what the minister has heard, rather than to demonstrate the minister's great wisdom about death and dying, the minister's words are likely to be effective in providing comfort. Comfort comes to the dying person first when she is given the opportunity to talk about the things she most needs to talk about, and second, when the minister listens, understands, and encourages her to say more (rather than taking over the conversation himself).

Suggestion #9: Plan for Future Visits

At the end of the visit the minister can talk with the dying person about what kind of schedule of visits she would like. The planning for future visits is done in a way that values the interdependence, embodiment, and vulnerability of both the dying person and the minister. Does she want the minister to wait for her to request a visit? Does she want the minister to come weekly? In this regard, the minister can be honest about his limits. It is important to commit only to what can be carried out. The minister can give people a general idea of the "ballpark" of his availability and ask where they fit, by saying, "I usually get around about once every other week, but some people like me to come every week, and others like me to come once a month. Some people want me to wait for them to call and ask me to visit. What sounds best for you?"

The length of the visit, likewise, has at its outside limit whatever both the dying person and the minister are able to offer. Perhaps the minister can offer an hour. The minister can indicate this, if it seems appropriate, at the beginning of the visit. The person being visited may be too ill or weak for that long of a visit, however. For this reason some visits with those who are dying need to be limited to about fifteen minutes.

Boundaries

Suggestion #10: Understand and Maintain Appropriate Professional Boundaries

Importance of Boundaries. This brings us to an important subject for consideration: boundaries. It is clear to those who work with the terminally ill that the dying and their families are incredibly vulnerable, due to the emotional upheaval taking place in their lives. There is the potential that the minister, or any other professional, may cause much harm if appropriate boundaries are violated. For this reason, additional attention will be given to this point.

In *Covenants and Care*, the authors state, "Boundaries are limits that allow for a safe interpersonal connection. Limits are often perceived as inhibiting a relationship, but healthy boundaries actually facilitate relating."[34] Without the confidence and clarity of this boundary, the person who is dying may not be willing to allow the minister to join as companion into the more vulnerable places of his life.

The Minister is Responsible to Keep Her Role Clear. Boundaries relate to the role of the minister, the definition of the relationship between the minister and the dying

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[34] Gary L. Harbaugh, Rebecca L. Brenneis, and Rodney R. Hutton, *Covenants and Care: Boundaries in Life, Faith, and Ministry* (Minneapolis: Fortress Press, 1998) 77.

person (and their loved ones), and the limits of that role and those relationships. While establishing a position of ministry which is supportive and alongside the dying person, the minister is a professional and not a friend or family member. It is the minister's responsibility to keep this clear.

At times a spouse of a dying person may say to a minister, "You are a member of our family; you mean so much to us." It is important that the minister understand that she really is not a member of the family, and be responsible to maintain the proper boundary that exists between families and professional caregivers. While perhaps letting the family continue to refer to her as "a family member," she should consistently refer to herself as their minister, and refrain from going beyond that role.

No romantic or sexual involvement. The minister should be aware of the human tendency to rationalize one's actions when one becomes attracted to another person. It is never appropriate for a minister to become romantically or sexually involved with a dying person or anyone else that the minister is counseling, nor with their loved ones whom the minister meets in the course of those visits. If the minister realizes that she is attracted to someone in this situation, she should seek assistance in order to maintain appropriate professional boundaries. In some cases, the minister can benefit from counseling to assist in "transference" issues. If necessary, in order to protect others from harm, the minister may at last resort need to remove herself from the situation and secure another minister to provide support to the dying person.

Ways to Maintain Boundaries. Ministers find a variety of ways to make sure that they observe appropriate boundaries. Being accountable to colleagues can be very helpful, especially if that includes a written commitment to maintaining professional

boundaries in ministry. Many ministers refrain from visiting anyone who is alone in an isolated environment.

By applying two simple limits consistently the minister can begin to establish the basic boundaries. First, the minister should limit the time spent with the person who is dying to the somewhat regulated period of time and frequency of visits which has been agreed upon with the person. The minister should be willing to provide for any one person the same time he is willing to provide for another person with similar needs, giving no "special treatment." This keeps the minister from becoming overly involved and also from wandering outside of the role of minister.

Second, the minister should limit the amount of personal information provided. The minister should talk about his own life only in bits when he believes that sharing a particular experience will aid in the companionship process. Besides helping the minister to maintain appropriate boundaries, this also helps prevent the temptation on the part of both the minister and the person who is dying to avoid the suffering of the one who is dying by shifting the focus to the minister's life. The minister is providing companionship in the life of the person who is dying; that person is not providing companionship in the minister's life. This does not mean that the visits and the relationship will not affect the minister or provide any benefits to the minister. The interdependent nature of the relationship, and the vulnerability of the minister, mean that the minister will be emotionally impacted. Often the minister shares in the joy of the human connection. At times, the visit may cause the minister emotional distress or difficulty. He must then turn to his own sources of support outside of this relationship, so that he is able to continue to provide support to the person who is dying.

5. DOCUMENTATION FOR PALLIATIVE SPIRITUAL CARE

After retiring at mid-life from parish ministry to enter a vocation of building houses, my Dad became very good at hitting a nail with a hammer. He won the nail-driving contest every year at the church picnic. He was good at hitting the nail right on the head, with maximum effectiveness. This is what is needed in palliative spiritual care—to hit the nail on the head in one's attempt to companion the dying—to hear and to respond in a way that helps those who are dying right at the point of need. The development of a blueprint can assist ministers in becoming more effective in their ministry with the dying, and this can be achieved through documentation.

Benefits of Documentation

Documentation can be useful to ministers for two important reasons. First, documenting the spiritual care can help the minister to become a better companion, with better abilities to hear accurately and to respond effectively. Having a discipline of sitting down to write about the visit encourages the minister to reflect on what is going on. I often have the experience that the person I visit makes an off-hand remark, and it is not until I sit down to reflect upon and to record the visit that I realize the significance of the remark. I can then look for an opportunity to revisit the remark with that person. The discipline of this process also helps me hone my listening skills for future visits. Second, documentation records the evolving plan of care, making it more likely that the care will

evolve into more effective care. It does this by giving the minister the opportunity to evaluate the effectiveness of each visit in relation to the goal of providing comfort. The care becomes more effective because it becomes more intentional.

Documentation can be viewed as a discipline which serves these purposes. The documentation is not an end in itself, merely a means to an end. Once the minister has fully developed the expanded levels of awareness and of intentionality which the documentation elicits, the documentation may be abbreviated according to the individual needs of the minister.

The Assessment

In order to provide effective palliative spiritual care, the minister must be constantly mindful, or intentional, in making an assessment of the places where it hurts, the sources of spiritual distress for the terminally ill person, as well as the sources of spiritual strength or relief. Every locus of spiritual pain involves grief and loss. When a person tells the minister about a loss in their lives, they are disclosing a source of spiritual pain.

There are multiple models of spiritual assessment tools available to clergy; several of the most popular (7 X 7, PLAN, HOPE, FICA, and others) are briefly noted in *Palliative Practices.*[35] The minister can modify one of these to fit the needs of the dying, or use the model offered here.

The first section of the assessment form provides space to fill in some of the basic contextual information about the person who is dying: name, address, phone, family information, church affiliation (here one can also note beliefs and rituals), and

[35] Kuebler, *Palliative Practices*, 326-327.

medical/psychological/social information. The purpose of paying attention to this sort of information is to enable the minister to understand the dying person in the context of the basic facts of his life: his family situation and culture, his church situation, and what else is going on for him medically, psychologically, and socially.

Next is a place to note the metaphorical places visited during the visit (beside the big lake, beside the busy creek, and beside the still waters). Third is a section with two parts: one part to note spiritual issues and places of spiritual pain noted during the visit, and one part to note sources of spiritual strength or joy noted during the visit. Finally, there is a section which incorporates the care plan: when the next visit is planned, and some tentative areas for exploration during the next visit.

Example of Assessment Visit And Documentation

Let us consider my visit to "Terry" as a way of illustrating the documentation of an initial visit, or assessment visit. Prior to my first visit to his apartment I gathered the following information: Terry is a 52 year old man who is cognitively impaired and functions at about an eight to ten-year-old level, he has cancer, and he lives in an assisted living facility.

When I knocked on the door Terry opened it part way and was initially hesitant to let me in. I explained why I was there, showed him my name tag, and he let me in. I had some difficulty understanding his speech at times. I noticed Cincinnati Reds memorabilia around his room and commented on it; this led him to talk at length about how they are doing this season. When I asked other questions he was more reticent.

Since he is a member of a Catholic church I offered to say a prayer for him before I left. He expressed that he would like that. I asked him if it is okay for me to come again in two weeks and he agreed.

Table 1 demonstrates, in compacted form, how this visit could be documented on an assessment form. (A blank copy of the full size form is provided in Appendix 1; it can be copied or modified to fit the minister's needs and preferences).

INITIAL PALLIATIVE SPIRITUAL CARE ASSESSMENT

Name of client: Terry Smith Phone: 555-5555
Address: 555 Fifth St, Washington
E-mail address: none
Family information: no living family; has case worker
Church affiliation (if any): St. Joseph; someone from there brings Communion
Med/Psych/Soc information: cancer, dev. delayed, assisted living

Metaphorical places visited during this visit (with brief explanation)

- Beside the Big Lake
  - Conversation about the Cincinnati Reds
  - The entire visit stayed here
- Beside the Busy Creek
- Beside the Still Waters

Spiritual issues / Sources of spiritual pain noted in this visit:

Unable to determine at this visit; Terry is reticent; unsure whether he really understands his prognosis

Sources of spiritual strength noted in this visit:

Church affiliation and support; finds joy in being a fan of Cincinnati Reds

Next visit / frequency of visits agreed upon: in 2 weeks
Potential area of focus for next visit:

Establish greater trust and encourage Terry to engage in conversation
Continue spiritual assessment

Date of visit: 5/5/03

Table 1

The Progress Note

The second form needed is a progress note, or a visit note. This form is used to document subsequent visits (after the initial assessment). It includes five sections. The first section notes the metaphorical places visited during the visit (beside the big lake, beside the busy creek, and beside the still waters). Since the minister knows she will want to write these things on this form after the visit, the form serves as a discipline to encourage the alongside, companioning position of the minister.

The second section provides a place to document places both of spiritual pain and spiritual strength or joy noted during the visit. The person who is visited may reveal issues and experiences in his life which cause him distress. The sources of the distress my be hurts from relationships, losses or disappointments in life, regrets over choices made or deeds done, current issues such as loneliness or a loss of a sense of meaning in life, a loss of a sense of dignity, and so on. Causes for celebration and gratitude, and sources of spiritual strength, may also emerge, and can be noted here.

The third area on the visit documentation form is a space to note comfort that was provided, and to note signs that comfort was experienced by the person who is dying. Often the comfort came through the experience of telling the stories and being fully heard. The person may give verbal or non-verbal indications that she indeed did feel heard and understood. The minister may have attempted to help the person find comfort through offering a ritual which respected the experience and wishes of the person visited. This, along with any observed response indicating how it was received, can be noted. People experience comfort, or interpret a visit as beneficial, for diverse reasons.

Finally, the form gives space for a care plan section which notes when the next visit will be and suggests tentative areas of focus, based on what has been observed in the visit and in the documentation process. The care plan is specific to the individual being visited and respects his wishes regarding the minister's visits.

Example of a Second Visit And Documentation

Let us consider a second visit with Terry to illustrate the form to document visits that follow the initial assessment visit. Two weeks after the initial visit, I returned for my second visit. Terry readily opened the door this time, and smiled in recognition when I said who I was. He took a relaxed position sitting on his bed and started talking immediately. He told me all of the things he had done to clean his apartment that morning, and that the work had tired him. He talked about the Cincinnati Reds again. He seemed to have difficulty understanding even basic questions, so I simply let him talk and joined in the conversation where he took it.

At the end of the visit, I once again offered to say a prayer, and he accepted. I said a prayer (mindful of Terry's Catholic faith), asking God to bless Terry. At the end of the prayer Terry spoke up again, this time telling me that he had cancer, and that he had been told that he might not live a year. I asked him how long he thought he would live, and he said, about a year. I asked him if he was afraid of dying, and he said yes, and that he hoped he would die in his sleep. I told him that most people with his type of cancer die in their sleep, and that I thought he would too. I also told him that we (hospice team) would take care of him and make sure he got medicine if he had any pain. He

appeared to be relieved by this. He returned the conversation to a social level by changing the subject. I agreed to return in two weeks.

Table 2 shows how this visit could be documented on a progress note. (A blank copy of this form is provided in Appendix 2).

PALLIATIVE SPIRITUAL CARE PROGRESS NOTE

Name of client: Terry   Date of visit: 5/19/03

Metaphorical places visited during this visit (with brief explanation):
- Beside the Big Lake
    - Conversation about the Cincinnati Reds
    - Most of the visit until the prayer
    - Closing remarks
- Beside the Busy Creek
    - Not noted this visit
- Beside the Still Waters
    - Conversation about his death after the prayer

Points of spiritual pain or spiritual strength noted:
- Terry's awareness of his disease and his terminal prognosis
- Terry's fear about what the dying process would be like

How comfort was provided:
- Heard and responded to Terry's fears, at his level (concrete information)

Signs that comfort was experienced:
- Terry's facial features relaxed noticeably, and he nodded his head

Plans for next visit: In 2 weeks
- Continue to build trust
- Follow up on the issues surrounding Terry's death
- Provide opportunity for Terry to bring up additional sources of distress
- Possibly pray earlier in visit to help Terry understand my role earlier in visit

Table 2

Both of these forms are models which may be adapted to each minister's style. The benefit to the minister comes through the discipline of sitting down and reflecting after each visit, in order to learn to become a better listener, to be more present, and to evaluate the effectiveness of the visit.

6. CONCLUSION: THE RESTORATIVE BENEFIT OF PALLIATIVE SPIRITUAL CARE

I will conclude this paper with some observations about the relationship between working with the dying and "burn-out." Frances Sheldon notes that "Burnout . . . has been found to be less common in hospice staff when they have been compared with mental health workers or oncology nurses."[36] She references studies which point to the ability of hospice staff to maintain appropriate distance, share frustrations with colleagues, and recognize that there are limits, "whether those are the limits of life itself, of individual personalities or of resources, and working creatively within limits . . . ."[37]

I would like to suggest two ways to avoid burnout, based on my observations of those who are able to continue working with the dying for many years. The two ways of avoiding burnout are directly related to this model of palliative spiritual care. As in the model itself, it is assumed that the minister already knows and applies basic strategies for self-care; these suggestions are specific to self-care when ministering with the dying and are not intended to constitute a complete self-care strategy.

An Achievable Goal Leaves the Minister With Less Stress to Manage

My first observation is that those who are able to continue working with the terminally ill on a long-term basis are those who have found a way to manage the stress,

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[36] Frances Sheldon, *Psychosocial Palliative Care: Good Practice in the Care of the Dying and Bereaved* (UK: Stanley Thornes, 1997) 127.

[37] Ibid.

the emotional package, related to death and dying. Although part of that may include strategies for coping with stress, I think that some have found a more proactive solution: they find an approach that leaves them with less stress to manage. If one cause of stress is the feeling that one has no control in a hopeless situation, then a key to lowering the stress is to choose goals that are humanly possible to achieve.

This brings us back to the goal of palliative care. When those who work with the dying are able to focus on the provision of comfort, and let go of futile goals, their stress level drops. In contrast, new hospice employees sometimes fall into a tendency to "try to do too much," often by being drawn into trying to solve the family's longstanding psychosocial issues, and then they find themselves emotionally overwhelmed a few months into the job. They will likely either learn to draw themselves into a focus on palliative care, or they will leave the job. Ministers likewise will find that adopting an approach of palliative spiritual care, with the achievable goal of providing comfort, leaves them with less stress to manage.

Moments of Companionship Restore the Soul

My second observation is that many of those who continue working with the terminally ill are able to do so because they have discovered a way to provide companionship to those who are dying in a way that invites moments "beside the still waters." The emotional energy resulting from these interchanges more than makes up for the emotional drain of this work. If caregivers are truly able to stop "chasing the wind," if they are able to emotionally accept the dying of the patient as well as their own human limitations, then they will be able to sit with the dying, beside the big lake, beside the

busy stream, and beside the still waters, where there is a sense of emotional restoration in the mutual sharing of "what is." There is the relief from the stress of feeling that one has to fix problems or to push the dying person to fix problems. There is an emotional benefit, or surging of energy, from these moments of true companionship.

I experience these moments as times when my own soul is restored.[38] This is perhaps an ancient truth which is found in the Judeo-Christian scriptures, in Psalm 23. The text reads, "He leadeth me beside the still waters. He restoreth my soul."[39] Since there was no punctuation in the original text, I take the liberty to translate the text in this way, "Beside the still waters my soul is restored."

Often, at the end of the day, as I talk about a special moment I experienced in ministry that day (always protecting confidentiality) I am surprised to hear the response of my family members. They hear the sadness in the story and can't quite seem to share my sense of joy and gratitude in what occurred in the visit. The difference is this: they are hearing a bit of a story from the life of a person who is dying and who is enduring much loss, while I was there for a moment of companionship and connection which brought relief and comfort to the person. So I am focused on the possibilities for comfort rather than the mountains which can not be moved, and I am grateful and even happy that the comfort that was possible did take place. I believe that this focus, and these experiences, are why the hospice employees are much more easy-going, light-hearted, and joyful than people suppose them to be.

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[38] By "soul" I refer to the psychological and emotional aspects of my being.

[39] Psalm 23:2b-3a, *The Holy Bible*, Authorized King James Version (Iowa Falls: World Bible Publishers, 1956).

In my frequent meetings with parish ministers I hear something similar in their work. The board meetings and the sermon preparation, even much of the pastoral counseling, can be tiresome at times. But when they experience a moment of depth in ministry, a moment of true companionship and connection, they are reminded of why they went into the ministry in the first place! It is beside the still waters, in these moments of ministry, that the soul of the minister is restored.

Appendix 1

INITIAL PALLIATIVE SPIRITUAL CARE ASSESSMENT

Name ______________________________ Phone __________________

Address ____

E-Mail Address ____

Family information

Church affiliation (if any) ___________________________________

Medical/Pschological/Social information

Metaphorical Places Visited during This Visit (with brief explanation)

Beside the Big Lake

Beside the Busy Stream

Beside the Still Waters

Spiritual Issues/ Sources of Spiritual Pain or Distress Noted in This Visit

Sources of Spiritual Strength or Relief or Joys Noted in This Visit

Next visit/ frequency of visit agreed upon ____________________________

Potential Areas of Focus for Next Visit

Date __________________

Appendix 2

PALLIATIVE SPIRITUAL CARE PROGRESS NOTE

Name of client ______________________________ Date of Visit _______________

Metaphorical Places Visited During this Visit (with brief explanation):

Beside the Big Lake

Beside the Busy Creek

Beside the Still Waters

Points of Spiritual Pain Noted During Visit

Places of Spiritual Support or Relief or Joys Noted During Visit

How Spiritual Comfort was Provided

Signs that Spiritual Comfort was Experienced

Date and Plans for Next Visit

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