Bridging hospice and church: preparing church members to be hospice volunteers

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BRIDGING HOSPICE AND CHURCH: PREPARING CHURCH MEMBERS TO BE HOSPICE VOLUNTEERS

By

Keith M. Wilks
Master of Divinity, Interdenominational Theological Center, 2008

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Doctor of Ministry
at
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ABSTRACT

BRIDGING HOSPICE AND CHURCH: PREPARING CHURCH MEMBERS TO BE HOSPICE VOLUNTEERS

by

Keith M. Wilks

May 2012

134 pages

There are a number of hospice patients and their families struggling through the end-of-life journey without the aid and comfort of a faith community. Some of these families have been separated from faith communities for many years. Hospice provides spiritual care to all patients who will accept chaplain support. However, there is still a place for the local church to join in the care plan for hospice patients and their families. As a Heartland Hospice chaplain and local pastor the researcher became aware there was a divide between Heartland Hospice and local churches in the area. This project was designed to build a bridge between hospice and the church by preparing church members to become hospice volunteers. The project design was to assist church members to dispel their myths about hospice, address unresolved fear of death and dying, and realize the need for a hospice volunteer ministry at the church. Project participants gained knowledge and experience in being hospice volunteers through hands on caring for ten hospice-patients from their church membership. This project has been instrumental in transforming Mount Carmel’s current hospice patient ministry within the congregation.
ACKNOWLEDGEMENTS

I offer my regards and blessings to all who helped and supported me during the course of this project. I would like to specifically acknowledge the following individuals:

I am extremely grateful to my project chair, Dr. Edward L. Smith, who received me into the Christian Church as my first pastor, spearheaded my first church appointment and whose supervision in this project enabled me to seek a deeper meaning in every phase of my work. I am heartily thankful to the project committee for your help and guidance in the rigor of academia.

I would like to show my gratitude to the staff of Heartland Hospice for daring to reach for new partnership in the care for patients and their families.

It has been an honor to work with the members of Mount Carmel who accepted the challenge of dispelling myths, addressing fears, and realizing the need for creative ministry.

I am forever indebted to my parents Al and Joan Wilks for their continuous love and encouragement. My experience of journeying with my mother in her end-of-life stage offered insight, inspiration, and an appreciation for this project more than words can articulate.

This project would not have been possible without my beautiful wife Adrian who has never ceased to love, encourage, and support me. I owe my deepest gratitude to you darling.
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CHAPTER 1

Introduction

This Dissertation encompasses the ministry setting and issues the researcher encountered as a hospice chaplain and local church pastor. The Doctor of Ministry Program has helped this researcher reflect critically on the art of ministry from a practical theological perspective. Using the practical theological method, the researcher will inform the reader of three key problems that hindered church members from pursuing a viable volunteer ministry to hospice patients: (1) Myths about hospice, (2) Mount Carmel church members' unprocessed fears, and (3) failure of the identified church to realize the necessity for an active volunteer ministry.

The project outlined in this work will give detailed steps about how the above three issues were addressed and reanalyzed, allowing project participants to become instrumental in caring for hospice patients. By using elements of biblical, theological, empirical and theoretical references and practices, the project’s purpose of preparing members to become hospice volunteers was achieved.

The project’s plan of action was outlined through collaboration between Heartland Hospice and Mount Carmel Christian Methodist Episcopal Church, consultation with hospice professionals, review of project-related literature, biblical and theological study, and much prayer. This project outlines the researcher’s hopes and expectations for change resulting in holistic care—that is to take into account all of somebody's physical, mental, and social conditions in the treatment of illness—to hospice patients and their families. Apparent in this endeavor was the necessity for the church to offer mission to those in the end-of-life journey, a goal which was met by participants. As
a result of this project, participants reported deep positive changes in their concepts of hospice, ability to process fears of death and dying, seeing the need to develop a hospice ministry, and becoming hospice volunteers. It was the author’s deepest desire to present a Dissertation Project that would offer an additional outreach ministry for Mount Carmel, create a supplemental resource to the pastoral care department of Heartland Hospice, and provide the benefit of a faith-based support for hospice patients and their families. Implementing this project has also transformed the researcher in numerous ways. As the researcher reflected, he realized he was intensely involved in this subject matter from a three-dimensional (3-D) view: (1) As participant as a chaplain and pastor; (2) observer as a Doctor of Ministry student, and (3) recipient of hospice, having a mother who recently died as a Heartland Hospice patient.

**Ministry Setting**

In 2010, hospice programs provided service to approximately 1.58 million patients. The National Hospice and Palliative Care Organization (NHPCO) “estimates that approximately 41.9% of all deaths in the United States were under the care of a hospice program” (NHPCO Facts and Figures 2011, 4).

The researcher’s ministry context was a chaplain within Heartland Hospice and also the pastor of a local congregation at Mount Carmel Christian Methodist Episcopal Church. Heartland Hospice is one of many hospices providing care to patients with a limited life expectancy and support to their caregivers. This care is designed to meet the physical, psycho-social, and spiritual needs of patients and caregivers. Hospice provides care to all who are eligible and in need of hospice care, irrespective of patients’ ability to pay. The service can be paid for by Medicaid, Medicare, private insurance, and private
pay or hospice can provide services without cost or maintain a patient for charity. A patient is likely eligible for hospice if the individual has been diagnosed with a terminal illness and can no longer benefit from a curative treatment program, and if the disease prognosis takes its usual course the patient could be dead in six months or less. Hospice offers support, care, and comfort to the terminally ill and their families; hospice is actively involved in all aspects of the patient's care.

The hospice team concentrates on providing comfort, pain and symptom management as well as spiritual and emotional support. The Hospice team includes: Patient Caregiver(s), Family/loved ones, Attending Physician, Hospice Medical Director, Administrator, Director of Professional Services, Volunteer Coordinator, Volunteers, RNs, Certified Nurse's Aides, Social Workers, Chaplains, and Bereavement Coordinators. This professional staff collaborates with the patient, family, and attending physician. Also, facility staff is involved in patient's care if the patient is residing in an extended care facility.

Hospice provides 24-hour, 7-days-a-week availability and support, individually tailored to meet the unique needs of each patient. The hospice team considers the entire family—not just the patient—as a "unit of care." Hospice helps the family and patient deal with any unresolved issues and assists them in coping with their feelings. Special bereavement care is available to the family for 13 months after the death of their loved one. The patient and family can decline all of the services or disciplines except nursing.

One chaplaincy ministry duty is to perform a spiritual care comprehensive assessment which evaluates the presence of support for the patient and family ranging from high, medium or low in the following areas: family, friend, community groups, and
religious groups. Using the assessment the chaplain attempts to gauge the level of preparedness for death for the patient and family. During the assessment the patient, family, and the chaplain also discuss end of life matters such as advance directives, do not resuscitate code status, and funeral arrangements. This is a method of identifying areas of support needed in the spiritual care of the patient and family. Theologically, hospice is expressing God’s will for humanity by offering comfort to one another, as the parable of the Good Samaritan brings to our understanding. According to Paul Irion, “Death is a very isolating experience. It involves the breaking of significant relationships. The dying person becomes aware that even though others are present, only he or she is dying. Some feel abandoned—by medical science, by friends, by God. Some people experience approaching death as a great loneliness” (Irion 1988, 22). Hospice is not about passing by the dying person, but being present and attending to individual needs. More will be said about the theological premises of this project in other sections of this document.

Heartland Hospice is located in Greenville, South Carolina and according to 2009 U.S. Census Bureau statistics, roughly 10% of the state’s population lives in Greenville County. Heartland, by law, services areas that are within a 60-mile parameter of the Greenville office. This is to ensure a staff member can respond in less than an hour during a patient crisis. Heartland serves patients in every age group, from infant to senior, of all ethnicities, faiths, and genders.

The local church involved in this research project was Mount Carmel Christian Methodist Episcopal Church in Anderson, South Carolina. Mount Carmel is a 130 year-old church apart of a 141 year-old denomination, the Christian Methodist Episcopal
Church. Mt. Carmel is located in a county of approximately 24,000 people, according to 2006 Census Bureau. The church is located in a mostly black, low income, and high crime neighborhood that is one of the oldest communities in the city. The average church attendance on Sunday mornings is forty to fifty-five people, who are predominantly black. The median age is 50; the average education level is a high school diploma. The gender ratio is about 3 to 1 female.

The organizational structure of the church is auxiliary-based. Each auxiliary is responsible to the church in general for its work. The theological characteristics of the church are in flux since there is an emerging group that is beginning to look critically at their faith utilizing the lens of liberation theology, and there is also a more theologically conservative group embracing embedded theology.

The congregation’s dialogue on the subject of death and dying had a significant impact on the church. A total of ten persons from Mt. Carmel have become hospice patients as a result of this project. Of those ten hospice patients, seven have died leaving seven church families, including the researcher’s family, experiencing parental losses. This project format helped provide awareness for participants and non-participants in the church to understand the benefit of hospice for their dying loved ones. Because of the expanded number of hospice patients within the congregation, project participants gained an early start in providing volunteer ministry. This direct engagement in and with hospice, along with the project format, helped the project participants to dispel their myths about hospice, resolve some fears of their own about death and dying, and realize firsthand the necessity of hospice volunteers for patients and their families.
The phenomenon of participants, families, and church members becoming hospice patients led to many interpersonal conversations in small groups to discuss private fears, concepts, traditions and theologies on death and dying. Because the researcher has a ministry in hospice, it was his desire to share the hospice experience with the congregation for the benefit of education and well-being in the matter of death and dying.

**Ministry Issues**

The purpose of the project was to stimulate Mt. Carmel to develop a ministry to the terminally ill and help members themselves to prepare for end of life issues. Therefore, the goals were to: (1) Dispel the myths about hospice, (2) help participants with unresolved fears of death and dying, and (3) help participants to articulate the need to have active volunteers at the church. Therefore, this project was designed to encourage a group of church members to become hospice volunteers. It is believed that this project will be a model for the universal church to emulate for more effective care of hospice patients in and outside of the church, to meet the missionary mandate of the church.

The U.S. hospice movement was founded by volunteers and there is continued commitment to volunteer service. The National Hospice Palliative Care Organization estimates that in 2010, 458,000 hospice volunteers provided 21 million hours of service. Hospice volunteers provide service in three general areas:

- Spending time with patients and families “direct support.”
- Providing clerical and other services that support patient care and clinical services “clinical support.”
- Helping with fundraising efforts and/or the board.
In 2010, most volunteers were assisting with direct support (59.3%), 19.2% provided clinical care support, and 21.5% provided general support.

Hospice is unique in that it is the only provider whose Medicare Conditions of Participation requires volunteers to provide at least 5% of total patient care hours. In 2010, 5.2% of all clinical staff hours were provided by volunteers. The typical hospice volunteer devoted 46.7 hours of service over the course of the year and patient care volunteers made an average of 201 visits to hospice patients (National Hospice & Palliative Care Organization statistics 2012).

The ministry issues presented by the researcher’s ministry context that were addressed are the separation of care between hospice and the church and the missed opportunity for the church to explore mission work to hospice patients and their families through volunteering efforts.

Researchers who studied minority use of hospice services often stressed the prevalent lack of information about hospice care among African Americans (Born et al., 2004; Jackson et al., 2000; Jenkins et al., 2005; Reese et al., 1999). In their interviews of African American pastors, Reese and colleagues (1999) found that most clergy members were not familiar with hospice care. Respondents indicated that many African Americans turn to their pastors for advice when a family member is terminally ill. It was noted that if pastors were unaware of services, it was highly unlikely that other African Americans would be aware that such care existed (Washington, et al. 2008, 272).

Each project session had to be designed to help the participants make the transformation from a curative to palliative point of reference. This was a major theological-psychological problem in moving church members from visitation of the sick to a hospice ministry. Curative care says “we will fix it.” Our society is bombarded with the notion if there is a medical problem, a pill, a specific treatment or a certain facility can provide the cure. Then there was the component of faith that will not allow Christians, at times, to
give up hope for healing. After all, in the church the participants had witnessed miracles and healings. This leads the church, in general, to pray for and visit the sick with the intention of healing being the ultimate outcome. On the other hand, hospice is directed towards palliative care methodology focusing on symptom management, relief of suffering and end-of-life care.

The researcher’s mother died as a hospice patient. It was extremely helpful and comforting for the researcher and his family to have a hospice-educated church accompanying them along his mother’s end-of-life journey. Furthermore, the researcher witnessed the sad struggle of some hospice patients without any faith-community support. With faith-community involvement the researcher believes patient-family challenges associated with the death and dying process could have been easier and more meaningful. The researcher desires to facilitate a greater holistic ministry to hospice patients and their families lacking ties to a faith community. The purpose of the project was to stimulate Mt. Carmel to develop a ministry to the terminally ill and help members themselves to prepare for end of life issues. To do this the researcher determined he had to: (1) Dispel the myths about hospice, (2) help participants with unresolved fears of death and dying, and (3) help participants to see the need to have active volunteers at the church. Therefore, this project was designed to encourage a group of church members to become hospice volunteers. The researcher thinks this project can be a model for the universal church to emulate, for more effective care of hospice patients in and outside of the church to meet the missionary mandate of the church.

Historically, Heartland Hospice has lacked a formal relationship with the faith community. There have been complications with some employees trying to evangelize
patients and their families and Heartland has left the task of contacting a faith community to patients and their families. However, hospice chaplains are available for families by request. Also historically the members of Mt. Carmel have understood hospice to be “a place where you go to die,” with hospice staff helping patients die. Through dialogue the researcher discovered Mt. Carmel members had very little personal experience with hospice, as well as no hospice volunteer experience. The researcher suspected the historical backgrounds of Heartland and Mt. Carmel represented a broader scale of separation between hospice and the church, therefore hindering partnerships.

**Theological and Biblical Undergirding**

Theological and biblical literature undergirded the project’s principles and practices. Mark 14: 32-42 is one example: Jesus was acutely aware that his death sentence was at hand. In his process of coming to grips with God and “self” regarding his end of life journey, he needed the disciples (church) to simply be present with him. Patients receiving a terminal diagnosis and their families can experience some of the same stages found in this text: anguish, bargaining with God, a sense of betrayal, and the need for someone to be present. Just as Jesus expected the disciples to actively participate by watching and praying, the same is expected for God’s people who find themselves or their loved ones in hospice due to illness. The ministry of presence can take on many dynamics for the hospice patient and family. There are times when sharing a challenging moment of a patient/family is all that is needed to express care for others. The researcher believes God’s will is that humanity stands together during crisis.

Matthew 25: 31-40: This parable reflects the importance of followers of Jesus the Christ or the resurrected Jesus to be vigilant in offering help to those whom are not in a
position of needing some help. In the article "Don't Let Them Die Alone" written by Joanne Webber, it is suggested that hospice care spirituality would benefit from greater Christian engagement. Webber says, "The church is not to miss this chance to serve those whose worth is no longer about productivity but primarily, and simply, about bearing God's image" (Webber 2009, 19). When the church is present to offer care at the end of life the imago Dei (Image of God) is reflected in the church, hospice patient, and family. When this occurs, all experience the authenticity of God's presence and activity in the lives of humanity.

Jesus is the primary member of the trinity in this research project; he is both participant and active observer. Jesus' death is recorded in such a way that it helps one realize the necessity of having a faith community present at one's death. Jesus also models what it means to see the imago Dei in others who are sick, dying, or cast out. How Jesus responded to his and other's death gives us a picture of methods of processing our mortality. The David Bosch book *Transforming Mission: Paradigm Shifts Theology of Mission* will provide strong theological premises for church mission in this project.

**Literary Resources**

Some of the operational literature utilized was from *Hospice and Ministry* by Paul E. Iron. This book explores pastoral care in hospice settings and how pastors and local church members can get involved. Another source is *Injustice and the Care of Souls* by editors Sheryle A. Kujawa-Holbrook and Karen B. Montagno. This book features articles regarding death and dying from a hospice perspective written by Webb Brown. Elisabeth Kubler-Ross' *On Death and Dying*, which includes the five stages of grief, will also be
used. The reader will discover additional literary material analyzed to examine the state of care for those in the process of death and dying.

This project brought together church and hospice in a new paradigm. As a result of this project, Mount Carmel discovered a new means of living out their mission to each other and to the community at large; the church can now refer members and others to hospice. Prior to the project, participants held myths about hospice and avoided seeing anyone on the service. As a result of this project, participants are prepared to become hospice volunteers and now have experience within their own family and/or church members in offering care to those who are in hospice are.

**Title of the Project**

The title of the project is “Bridging Hospice and the Church: Preparing Church Members to be Hospice Volunteers.” This title is based on the need for hospice and the faith community to reflect on and seek bridging their existing separation.

**Outlining the Project**

It was the researcher’s speculation, that if the church and hospice developed a strong connection together, they would provide a more holistic approach to the plan of care for more patients and their families. Furthermore, the local church would receive the benefit of carrying out its mission to itself and the world. Therefore, congregational education in the episodes, situations, and contexts surrounding end-of-life matters was necessary. Church members needed to reframe their concept of hospice. It was an opportunity for the participants to develop tools to utilize in coping with their fear of death and dying. The steps and goals were to execute a series of five dialogical sessions
between church members, pastor, and hospice professionals, including five feedback sessions with the researcher, participants, and hospice staff following the sessions.

1. Session one: Pastor, church members, social worker, nurse, bereavement coordinator, and chaplain discussed “What is Hospice?” The session goal was to dispel the myths and learn facts about hospice.

2. Session Two: Pastor, church members, and medical director discussed end of life issues, preparation, and choices. The goal of this session was to help members prepare for end of life decisions.

3. Pastor, project participants, chaplain, bereavement coordinator, and nurse discussed the dying process. The goal was to help the participants understand fears of death and learn Kubler Ross’ five stages of grief.

4. Pastor, chaplain, social worker, nurse and participants discussed, “Stigmas attached to AIDS and other diseases.” The goal was for members to learn about universal precautions, increasing some participants’ comfort level with ministering to AIDS patients and other patients with communicable diseases.

5. Pastor, chaplain, volunteer coordinator, and participants discussed “Church Mission to the Dying: The opportunity and need for volunteers.” The goal was to help participants realize the need for church outreach to hospice patients and their families.

Objectives and Purpose: (1) To help participants gain a better understanding of hospice, (2) To assist participants in considering their own mortality and develop coping skills, (3) To help participants realize the benefit of hospice volunteers. The Cost of the project:
The cost included $150/ hour for the doctor, $75/ hour for the nurse, and $50/ hour for each social worker, bereavement coordinator, and chaplain to offer workshops.

In this project the researcher worked with a group of eight members at Mt. Carmel Christian Methodist Episcopal Church and staff from Heartland Hospice. Church members participating in the project demonstrated an interest in learning about and assisting hospice patients and staff at Heartland Hospice. The researcher selected staff from Heartland who had direct patient contact and wanted to participate in bridge building between hospice and the church.

The researcher hoped to bring change to the way in which members explored or chose not to explore the end-of-life episodes, situations, and contexts that are generally a part of the grief process. In the end of life journey, it is common for patients to experience loneliness, fear, and confusion regarding the decline in their health (Why am I not getting better?). The end of life journey brings about the reality of separation from the familiar and a movement towards the unknown in the patients and their family. In the process, the person dying can experience the pain involved in their change of self-definition. End of life journey can lead to more dependence on others than what patients and their families have been accustomed to. The patient in some cases is unable to perform activities of daily living that were so easy, prior to their illness; this can cause their self-esteem to decline significantly adding to the loneliness, fear and confusion. In some patients, the question arises: how can I survive if I cannot take care of myself? Another question that appears to be common is: will my caregivers get tired of attending to my needs?
Then, there is the families’ journey in the end of life episodes, situations, and contexts. The researcher never thought he would take care of his mother in her end of life journey. Many families have not had dialog on how they would handle this journey. In hospitals and in hospice care there are instances when the patient can’t speak for themselves as they potentially approach death. The researcher has seen family members experience conflict and anguish when faced with making choices of extending mechanical life support or allow a natural death. In the researcher’s view, there can be a ministry of presence offered that can bring comfort to patient, family and caregiver in the end-of-life episodes, situations, and contexts.

In general, members without hospice experience believed if you were on hospice, then you were speeding up your dying process. Thus, creating a sense of urgency is necessary within the congregation to partner with hospice for a shared ministry to assist those facing death and dying. To achieve these changes transactional leadership was required.

The project was not designed to carelessly send volunteers to patient homes, but to gradually help participants come to grips with the spiritual, psycho-social, and physical dimensions connected to patients/loved ones with terminal diseases. As the subject matter of the sessions attended to the internal development of the project, participants became better equipped in matters of death and dying.

The researcher also envisioned that the Heartland Hospice team would experience transformation by valuing the hospice-educated church members as part of the patient/family care team. Each hospice staff member who participated in the project expressed they were indeed changed by the experience: they each had a deeper
understanding of the need to bridge hospice and church. It is the researcher's hope and prayer Heartland Hospice will continue partnering with Mt. Carmel for the holistic care of its patients by including the church as a resource available to hospice patients and their families.

The researcher evaluated the effectiveness of the program—from the beginning of the project to the middle and end—through collecting and analyzing data through observation, qualitative methods, group and individual interviews following each session, and written comments from questionnaires. Questionnaires (Appendix A) were completed by participants at the beginning and end of the program. The questions aided the researcher with gauging the effectiveness of project. The questionnaire included a section for narrative feedback. The researcher held feedback sessions to assess the group's information processing and overall experience.

The participants began to understand missionary ventures of the church—Bosh's "missiones ecclesiae"—and how the church by its nature should be available to hospice patients needing a faith community. This partnership with hospice included reframing concepts of death and dying along with exploring the role of hospice in the community.

As Dr. Paul Irion wrote "Hospice functions in our contemporary pluralistic and secularized society, where not all patients and families are deeply rooted in a faith community" (Irion 1988, 42). Hospice is designed to be holistic; therefore, hospice should no longer neglect action towards partnership with the church. With the church seeking hospice and hospice seeking the church, enhanced care for terminal patients and their families will be achieved.
Researcher’s Motivation

The researcher’s concept of death and dying has expanded through reflection, dialogue, observation, experience in this project, including writing this dissertation. The researcher began his chaplaincy at a metropolitan hospital in Atlanta and the experience exposed him to death and dying beyond the pastorate. Since the hospital was a level two trauma center, he attended traumas regularly: he was present at a number of deaths and accompanied doctors as they told family members their loved ones had died. Also, in the course of his chaplaincy duties the researcher saw many people of faith come to end-of-life situations with very little reference theologically, psycho-socially, spiritually, or emotionally.

From hospital chaplaincy the researcher entered hospice as a chaplain and once again witnessed people of faith unequipped for the death and dying process. Upon reflection on many years in the pastorate, he realized he had preached many sermons on after-life and taught on heaven and its beauty, but he had never preached one sermon or led a study on the dying process—not to mention advanced directives or Do Not Resuscitate orders. At some point in his reflection the researcher promised God and self he would pass along information and invite others to inform congregations about the death and dying process. This project has helped the researcher and others to discuss death and dying in group and individual settings.

As a hospice chaplain the researcher has offered ministry to patients and families lacking a faith community to companion with them in the end-of-life journey. He is convinced some of these patients and families may have benefited greatly from a faith community volunteer partnering in the plan of care. Heartland Hospice and other
hospices provide the best ministry they could offer; however, the researcher experienced a longing for the church’s presence.

The researcher’s mother, Joan Wilks, died as a patient of Heartland Hospice. The experience of being a family member of a patient will always be etched in the mind and heart of the researcher. The researcher valued the patient support of Mount Carmel as they provided presence alongside him and his wife in his mother’s end-of-life journey.

A project goal was to facilitate faith community support for families during an end-of-life context. Without question this goal was realized in a phenomenon that could only be called Divine intervention in this project. Through the providence of God the participants were able to share end-of-life ministry with eight church members who were admitted into hospice during the length of the project. This project contributed to participants and researcher’s theological, psychosocial, and professional growth that enhanced their concept of God, self, and others in the death and dying process and church mission.
CHAPTER 2

Biblical Review

Understanding the need for the Project

One of the most difficult realities that theologians and health care professionals face is that some patients will die. According to Dame Cicely Saunders the founder of modern hospice “Although we cannot change this fact, we may have a significant and lasting effect on the way in which people live until they die” (Saunders 1982-83, 91). The manner in which an individual’s death occurs and the enduring memory of that death for the family is extremely important. In the past four decades there has been a surge of interest in the care of the dying, with the emphasis on the settings in which death occurs, the technologies used to sustain life, and the challenges of trying to improve end-of-life care. Hospice, which originated in Great Britain, best addresses the needs of those whose death is imminent.

Hospice is a coordinated program of interdisciplinary care and services provided both in the hospital and in the home to terminally ill patients and their family members. The needs of patients with terminal illnesses are many and best met by a comprehensive multidisciplinary program that focuses on quality of life, palliation of physical symptoms, psychosocial and spiritual support for the patient and family members when death is inevitable. Hospice care can be provided in several settings such as in a free standing hospice center, community hospitals or home based setting. Predominately, hospice care is delivered at home when at all possible. Many individuals who are hospitalized may also receive spiritual care but miss the opportunity to be connected to the church and or church family. Frequently, there is no “church” link between patients undergoing
hospice care in the hospital or hospice settings. Therefore, the purpose of this project is to prepare a select group of church members to become hospice volunteers to provide specific care for patients who are currently admitted onto the hospice service.

The Gospel of Mark 14:32-42

The Bible does not use the term hospice, however, the selected text in Mark 14:32-42 contain many similarities of hospice:

[32] They went to a place called Gethsemane; and he said to his disciples, Sit here while I pray. [33] He took with him Peter and James and John, and began to be distressed and agitated. [34] And he said to them, I am deeply grieved, even to death; remain here, and keep awake. [35] And going a little farther, he threw himself on the ground and prayed that, if it were possible, the hour might pass from him. [36] He said, Abba, Father, for you all things are possible; remove this cup from me; yet, not what I want, but what you want. [37] He came and found them sleeping; and he said to Peter, Simon, are you asleep? Could you not keep awake one hour? [38] Keep awake and pray that you may not come into the time of trial; the spirit indeed is willing, but the flesh is weak. [39] And again he went away and prayed, saying the same words. [40] And once more he came and found them sleeping, for their eyes were very heavy; and they did not know what to say to him. [41] He came a third time and said to them, Are you still sleeping and taking your rest? Enough! The hour has come; the Son of Man is betrayed into the hands of sinners. [42] Get up, let us be going. See, my betrayer is at hand (New Revised Standard Version Bible).

The passion narrative is the central biblical reference which the researcher selected to undergird this project. The Gospel of Mark has been the researcher's favorite New Testament writing. He always starts Bible study in a new parish with this Gospel. The author concurs with Ben Witherington, III as he wrote, “It may come as something of a surprise to know that the Gospel of Mark was neglected from Christian history for at least from the early Middle Ages until the nineteenth century” (Witherington 2001, 1). Just as the Gospel of Mark has been overlooked, so has the need of multidisciplinary care for persons who are in the dying process. It was not until 1967 when Physician Dame Cicely Saunders, founded one of the first modern hospice centers in Europe. In the gospel of
Mark, Jesus is the central figure. From the beginning, this gospel highlights Jesus’ virtuous actions and words until his untimely death. The gospel of Mark definably focuses on the passion surrounding Jesus’ death. Mark spends 19% of the book on the passion compared to 15% by Matthew and Luke. Mark’s Gospel has been called a passion narrative with a long introduction, because Jesus, like all human beings, faces His death in the Garden of Gethsemane.... in prayer, blood and sweat (Witherington 2001, 5). Mark 14:32-42 relates to this project from a Christological, Anthropological and sociological perspective.

**Christological Critique**

From a Christological critique, this text was perceived as problematic to some theologians such as Ambrose of Milan (ca. 339-397) and Thomas Aquinas (ca. 1225-1274): “Premodern interpreters, at least those with ‘orthodox’ Christological sympathies, were disconcerted that, among other things, Jesus appeared in Gethsemane in a pose of weakness and reliance upon his Father’s powers. Few ancient exegesis expressed the disturbing implications of this feature of the narrative” (Madigan 1995, 2). It can be hard to rationalize that Jesus has opened blind eyes, raised the dead and considered able to do all things, now acting in a posture of weakness. However, in this text, it is apparent that Jesus is struggling with end of life issues. One might say, Jesus is mirroring a person that has received a terminal diagnosis in this narrative. Just as Ambrose and Aquinas find it problematic for Jesus to be in this condition, so do patients who once were healthy and in some way had a “Christ like” sense of immortality, now are dying....sad and maybe even fearful. As Paul Irion writes, “In a society that highly prizes vitality, illness can be very demeaning and dying the ultimate indignity” (Irion 1988, 28).
The researcher agrees with Karen Smith as she raises the thought “Deep within us, we know that we, too, have been to Gethsemane. At one time or another, we have prayed, ‘O God, please, everything is possible to you, if you will....' (Smith 1991, 434). We pray for healing of a body ravaged by disease. We pray for restoration of relationships in broken and dysfunctional families. At some point, perhaps, we have prayed for a moment free from regret. As we face the unknown future, and as we seek to cope with all the uncertainties of life, we too pray, "God if you will . . . ." (Smith 1991, 434).

We are familiar with the Gethsemane prayer, and yet the words found on the lips of Jesus in Mark's Gospel may leave some of us uneasy. It is difficult for us to picture the Son of God uttering those words. Some scholars, according to Smith, have tried to soften the passage by saying that Jesus did not ask to be delivered from suffering, but rather shrank from evil. Others say that Jesus was reacting to death, but then question how one who feared death could be divine (Smith 1991, 434).

**Anthropological Critique**

In her book, *On Death and Dying*, Elisabeth Kubler-Ross MD outlines five stages of grief that persons commonly exhibit at the end of life. The five stages are: 1. Denial- “I feel fine,” “This can’t be happening to me.” 2. Anger- “Why me?” 3. Bargaining- “I’ll do anything for a few more years,” “I’ll give my life’s savings.” 4. Depression- “I’m so sad, why bother with anything?,” “What’s the point.” 5. Acceptance- “It’s going to be okay,” “I can’t fight it, and I may as well prepare for it.” Kubler-Ross makes clear these stages may not happen in an exact order but they commonly manifest in dying persons. It is this researcher’s contention that in chapter 14 of the Gospel of Mark that Jesus exhibited “moderate” signs of the five stages of grief in this narrative. These stages include, Depression (verses 33-35a), Bargaining (verses 35b- 36), Anger (verse 37-38 & 41), Denial (verse 39) and Acceptance (verse 42). There is certainly room to argue the
researcher’s critique. The researcher believes there is further anthropological research needed on this text. However, for the purpose of the project, the volunteers memorized the five stages of grief as part of their sessions with the hospice professionals. In addition, it will be important to their ministry as volunteers to be aware of the possible psychosocial components patients may experience.

**Sociological Critique**

The final critique relating to this pericope is Sociological. According to Irion, “Death is a very isolating experience. It involves the breaking of significant relationships. The dying person becomes aware that even though others are present, only he or she is dying. Some may feel abandoned by medical science, by friends, and even God. Some people experience great loneliness as they approach death” (Iron 1988, 22).

In the Markan text, Jesus takes the disciples with him so they may offer the ministry of presence. He does not ask them to go with him to talk to God and there is no indication what he wants them to do other than to “Sit here while I pray (v34).” There is the possibility Jesus is wrestling with a sense of being abandoned by friends and later in the passion narrative he expresses the feeling that God has abandoned him (15:34). This text helps to unfold the need for a representative from faith community to not let people die alone. Joan Webber put it best, “Instead of requiring the weak and hopeless to seek us out, we should be seeking them out, bringing with us the presence of Christ. And, if sensitively timed and led by the Holy Spirit, we may be asked to speak of the ‘reason for the hope that you have’—even in the face of death. It is the unique Christian hope in the “Resurrection” that should compel us to share it with those who need it most” (Webber 2009, 19).
Mark 14:32-42 relates to this project in varying dimensions. From the Christological problem, the text mirrors how dying can afflict the once healthy individual. Also, from an anthropological standpoint, the narrator could not have heard from anyone what Jesus was going through in his dialog with God, after all, those who were closest to him, were sleeping. Yet with a creative understanding and experience with how people approach death in common, the narrator painted what was thought to be an appropriate response from Jesus. The cry is one of a social nature from Jesus and from current hospice patients, “watch with me.”

Matthew 25: 31-46

As we explore the Gospel of Matthew, the researcher examined and found a correlation in Matthew 25: 31-46 and the development of a ministry to hospice patients by church volunteers. The Matthew text is as follows:

When the Son of Man comes in his glory, and all the angels with him, then he will sit on the throne of his glory. [32] All the nations will be gathered before him, and he will separate people one from another as a shepherd separates the sheep from the goats, [33] and he will put the sheep at his right hand and the goats at the left. [34] Then the king will say to those at his right hand, 'Come, you that are blessed by my Father, inherit the kingdom prepared for you from the foundation of the world; [35] for I was hungry and you gave me food, I was thirsty and you gave me something to drink, I was a stranger and you welcomed me, [36] I was naked and you gave me clothing, I was sick and you took care of me, I was in prison and you visited me.' [37] Then the righteous will answer him, 'Lord, when was it that we saw you hungry and gave you food, or thirsty and gave you something to drink? [38] And when was it that we saw you a stranger and welcomed you, or naked and gave you clothing? [39] And when was it that we saw you sick or in prison and visited you?' [40] And the king will answer them, 'Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me.' [41] Then he will say to those at his left hand, 'You that are accursed, depart from me into the eternal fire prepared for the devil and his angels; [42] for I was hungry and you gave me no food, I was thirsty and you gave me nothing to drink, [43] I was a stranger and you did not welcome me, naked and you did not give me clothing, sick and in prison and you did not visit me.' [44] Then they also will answer, 'Lord, when was it that we saw you hungry or thirsty or a stranger or naked or sick or in prison, and did not take care of you?' [45] Then he will answer
them, 'Truly I tell you, just as you did not do it to one of the least of these, you did not do it to me.' [46] And these will go away into eternal punishment, but the righteous into eternal life" (New Revised Standard Version).

**Emphasis on Attitude**

According to Sigurd Grindheim, the Matthew text focuses on righteousness through deed and attitude. Grindheim stated “Read in light of the rhetoric of the whole Gospel, I will argue that this passage brings together Matthew’s emphases both on a higher righteousness and on the helplessness of the disciples. I will argue that the two groups in Matt 25:31-46 are distinguished not only by their works, but also by their attitudes, and that their different attitudes explain their different actions” (Grindheim 2008, 314). That is why in the project it was so important to help dispel myths about hospice creating an enhanced awareness of the hospice philosophy. The researcher believes that the participants would have a healthy attitude about volunteering for hospice.

**Church Mission**

According to Emmanuel M. Jacob, “Christian mission is the response of Christians to the presence of God, and their participation in God's action to liberate all people. Mission is solidarity with God and neighbor, and with the God who is with our neighbors, and participation in that divine project quite rightly called the missio Dei” (Jacob 2002, 102). In the Matthew text, Jesus identified himself with those who were the least or in need. He saw beyond their situation and into their core selves. To be in authentic solidarity in the dying moment with another, one must understand human connectedness. In that space, differences become blended with commonalities. There is a sense of being invited, there is clarity when the Divine is present and the encounter has a
sense of mysticism. When it is clear, we are sharing in the missio Dei or as Bosch calls it
"The missions ecclesiae: the missionary ventures of the church" (Bosch 199, 10).

**Bridging and Connecting**

The researcher utilized the paradigm in Matthew’s New Testament community
conditions between Jewish and Gentile Christians to assist in developing a project bridge
between church-hospice. In the Matthew text, there were clear differences in Jewish and
Gentile Christian heritages, socio-economic status and theological concepts. The writer of
Matthew chooses both Jewish and Gentile prominence in the gospel, instead of playing
one against the other. In fact the writer directs his theological mission to both Jews and
Gentiles. Therein neither group is excluded, making it possible for each group to
“embrace each other” (Bosch 1991, 60).

The disconnection between the church and hospice may be due to a lack of
communication. Hospice and church could lead to a very powerful mission to the world
by pursuing a goal to enhance commonalities and accept differences. Both hospice and
the church universally believe no one should die alone. Both advocate for dignity in life
and death and both promote the importance of spirituality and relationship with the
Divine.

Another vantage point is both death and dying are very uncomfortable for many
people, including those in church and hospice. Perhaps some church members have not
been equipped to approach death and dying situations with ease. Although there is much
discussion about heaven in church, there is very little dialogue about the dying process or
end of life. Their unprocessed fear of death and dying could be a factor why churches do
not seek relationships with hospice centers. In contrast, hospice leans more to the clinical aspect of death and dying.

The overall theme of Matthew can be viewed as a writer’s attempt to bridge and connect the two communities of the Jewish and Gentile Christians. From this backdrop, the pericope Matthew 25: 31-46 can be interpreted as an attempt to highlight the importance of bridging and connecting those who are suffering with the ones that can provide some comfort. Jesus’ reference to the King helps us realize God is present and active though not always understood to be there and watching.

It is the researcher’s belief that church and hospice have different mandates and missions. However, this project was a catalyst for a dialog that will continue for the benefit of hospice patients and families, hospice staff and church members.

**John 14:1-14**

“Farewell Discourse”

John 14 verses 1-14 are called the ‘Farewell Discourse’ by some scholars:

[1] "Do not let your hearts be troubled. Believe in God, believe also in me. [2] In my Father's house there are many dwelling places. If it were not so, would I have told you that I go to prepare a place for you? [3] And if I go and prepare a place for you, I will come again and will take you to myself, so that where I am, there you may be also. [4] And you know the way to the place where I am going." [5] Thomas said to him, "Lord, we do not know where you are going. How can we know the way?" [6] Jesus said to him, "I am the way, and the truth, and the life. No one comes to the Father except through me. [7] If you know me, you will know my Father also. From now on you do know him and have seen him. [8] Philip said to him, "Lord, show us the Father, and we will be satisfied." [9] Jesus said to him, "Have I been with you all this time, Philip, and you still do not know me? Whoever has seen me has seen the Father. How can you say, 'Show us the Father'? [10] Do you not believe that I am in the Father and the Father is in me? The words that I say to you I do not speak on my own; but the Father who dwells in me does his works. [11] Believe me that I am in the Father and the Father is in me; but if you do not, then believe me because of the works themselves. [12] Very truly, I tell you, the one who believes in me will also do the works that I do and, in fact, will do greater works than these, because I am going to the Father."
[13] I will do whatever you ask in my name, so that the Father may be glorified in the Son. [14] If in my name you ask me for anything, I will do it.

In this section of the “Farewell Discourse” Jesus is preparing his disciples for his death and departure. The biblical motif of preparing those who remain prior to death is found in Joshua [23:14] “And now I am about to go the way of all the earth, and you know in all your hearts and souls, all of you, that not one thing has failed of all the good things that the Lord your God promised concerning you; all have come to pass for you, not one of them has failed (New Revised Standard).” And also in 1 Kings 2:2-4 when David gives a “Farewell Discourse:”

[2] I am about to go the way of all the earth. Be strong, be courageous, [3]and keep the charge of the Lord your God, walking in his ways and keeping his statutes, his commandments, his ordinances, and his testimonies, as it is written in the law of Moses, so that you may prosper in all that you do and wherever you turn. [4]Then the Lord will establish his word that he spoke concerning me: If your heirs take heed to their way, to walk before me in faithfulness with all their heart and with all their soul, there shall not fail you a successor on the throne of Israel.

As in the case with Joshua, David and Jesus, so are many hospice patients compelled to leave a message of great value for the ones left behind. Hospice patients “Farewell Discourse” are left with family members, friends, staff and volunteers. There are many patients that desire to have spiritual conversations with others, and there are no better people to have that conversation with than members of a faith community. This project was not designed for participants to learn how to impose their theology on hospice patients or their families. However, if patients or families bring up spiritual issues church members are encouraged to actively listen and respond to the best of their ability and or refer to the pastor or chaplain. There is a faith component to being present
without imposition. The project participants learned offering words of encouragement with acts of care is a missionary endeavor pleasing to God.

“In John's understanding, "saying" and "doing" holds together as one: "The words that I speak to you, I do not speak from myself, but the Father who dwells in me does his works.” So John's Gospel has made plain to this point. Revelatory deeds are explained through revelatory words.” The healing of a paralytic is the occasion for a discourse on Jesus as the one who continues the Father's work of "giving life" and "bringing judgment" (chap. 5). The feeding of the large crowd points to Jesus as the "living bread, who has come down from heaven to give life to the world" (chap. 6). As "the resurrection and the life" he raises Lazarus from the dead, and those who live because they believe in him shall never die: cessation of this present life only leads to resurrection unto final eternal life” (Gordon 1989, 172).

In this pericope Jesus is utilizing what he says and what he does as proof of his and God's connection. He also invites the disciples to join him in aspiring to Christ like action and to go beyond. “These words from John 14:12 set the stage for a non-competitive and adventurous understanding of the relationship of divine and human agency and invite persons to expect greater things of themselves as well as greater things from God in the ongoing, dynamic, and symbiotic divine-human call and response” (Epperly 2010, 45). In the overall “Farewell Discourse” Jesus offers assurance that even though he is leaving, the “Advocate” would come and empower the disciples. Through prayer, research of the literature and dialog the Holy Spirit was at the heart of this project. The Holy Spirit empowered the participants to dispel their myths about hospice, face their fears of death and dying and see the need for hospice volunteers from the local
church. What was most incredible was how the Holy Spirit empowered participants and
the researcher to apply the project principles and faith in God in our own homes as we
wrestled firsthand with the death and dying of our family units.

The biblical review was invaluable for the researcher in developing theological,
psychosocial, and practical design for the rationale of the project. It was a guide in aiding
the researcher and participants to reach the purpose of addressing the myths of hospice,
fears of death and dying and helping church members in seeing the need for hospice
volunteers in the congregation.
CHAPTER 3

Theological Review

Ministry Context

The researcher’s ministry context is a chaplain with Heartland Hospice and also the pastor of a local congregation at Mount Carmel Christian Methodist Church. Heartland Hospice is one of many hospices providing care to patients with a limited life expectancy and support to their caregivers. This care is designed to meet the physical, psycho-social, and spiritual needs of patients and caregivers. Hospice provides care to all who are eligible and need hospice care, irrespective of patients’ ability to pay. The service can be paid for by Medicaid, Medicare, private insurance, and private pay or hospice can provide services without cost or maintain a patient for charity. A patient is likely to be eligible for hospice if the individual has been diagnosed with a terminal illness and can no longer benefit from a curative treatment program. If the disease prognosis takes its usual course the patient could be dead in six months or less. Hospice offers support, care, and comfort to the terminally ill and their families and is actively involved in all aspects of the patient’s care. The hospice team concentrates on providing comfort, pain and symptom management as well as spiritual and emotional support. The Hospice team includes: Patient Caregiver(s), Family/loved ones, Attending Physician, Hospice Medical Director, Administrator, Director of Professional Services, Volunteer Coordinator, Volunteers, RNs, Certified Nurse’s Aides, Social Workers, Chaplains, and Bereavement Coordinators. This professional staff collaborates with the patient, family, attending physician, and staff (if patient is residing in an extended care facility). Hospice provides 24-hour, 7-days-a-week availability and support, individually tailored to meet
the unique needs of each patient. The Hospice team considers the entire family—not just the patient as a "unit of care." Hospice helps the family and patient deal with any unresolved issues and assists them in coping with their feelings. Special bereavement care is available to the family for 13 months after the death of their loved one. The patient and family can decline all of the services or disciplines except nursing.

A hospice chaplain duty is to perform a spiritual care comprehensive assessment which includes the degree of support for the patient and family ranging from high, medium or low in the following areas: family, friend, community groups and religious groups. Using the assessment the chaplain will attempt to gage the level of preparedness for death of the patient and family. During the assessment the patient, family and chaplain also discuss end of life matters such as advance directives, do not resuscitate, and funeral arrangements. This is a method of identifying areas of support that will be needed in the spiritual care of the patient and family.

**Ministry Issue**

The ministry issue was the separation of hospice and church. Two key problems resulting from this issue were the following: Some hospice patients and their families had no faith community to accompany them in their end of life journey. Another pressing problem was the opportunity that the church was missing to provide valuable mission service. It was the researcher’s speculation that if the church and hospice developed a strong connection they would provide a more holistic approach to the plan of care for more patients and their families. As a result of the project there was collaboration of care which provided a more holistic care plan for hospice patients who were members of Mount Carmel. In addition, the local church received the benefit of carrying out its
mission as a source of God’s love and care. To achieve this, the congregation needed more education about the episodes, situations and context surrounding end of life matters. It was clear the church members participating in the project needed to reframe their concept of hospice by removing myths, exploring fears of death and dying, and realizing the need for hospice volunteers.

**Bible Verses and Theology**

Mark 14: 32-42 is one example: Jesus was acutely aware that his death sentence was at hand. In his process of coming to grips with God and “self” regarding his end of life journey, he needed the disciples (church) to simply be present with him. Patients receiving a terminal diagnosis and their families can experience some of the same stages found in this text: anguish, bargaining with God, a sense of betrayal, and the need for someone to be present. Just as Jesus expected the disciples to actively participate by watching and praying, the same is expected for God’s people who find themselves or their loved ones in hospice due to illness. The ministry of presence can take on many dynamics for the hospice patient and family. There are times when sharing a challenging moment of a patient/family is all that is needed to express someone cares. God’s will is that humanity stands together during crisis.

Matthew 25: 31-40: This parable reflects the importance of followers of Jesus the Christ or the resurrected Jesus to be vigilant in offering help to those whom are not in a position of needing some help. In the article “Don’t Let Them Die Alone” written by Joanne Webber, hospice care spirituality would benefit from greater Christian engagement. Webber says, “The church is not to miss this chance to serve those whose worth is no longer about productivity but primarily, and simply, about bearing God’s
image” (Webber 2009, 19). When the church is present to offer care at the end of life the imago Dei is reflected in the church, hospice patient, and family. When this occurs all experience the authenticity of God’s presence and activity in the lives of humanity.

Attached to the latter text is the theology found in Mark 1:40-42, Jesus reaching and touching the leper. In hospice there are persons with full-blown HIV who have been shunned because of stigmas and fears similar to lepers in Jesus’ day. It is incumbent upon the church to encounter hospice patients with disease like AIDS because the Imago Dei is never out-shined by any disease or diagnosis. How isolated physically, spiritually and emotionally it must be when a person is dying and others will not touch or hold them because of fear and loathing. A degree of Christ’s healing was manifested in breaking the leper’s seclusion through acceptance and touch. Following the Jesus model the church can make a difference in the lives of many patients and their families by sharing in Christ’s act of acceptance and touch regardless of disease or diagnosis.

John 14:8-12: There is an expression of an incarnational relationship in this text. Jesus states if you see him you see God because God dwells in him. He goes further to infer God dwells within us. Therefore it is biblically and theologically sound for the church to be birthed by the Holy Spirit in a new relationship with hospice. The church should specifically enter into this relationship with the intent to bring transformative action emanating from God, Jesus, and the Holy Spirit. The opportunity for shared philosophy, theology along with other concepts would meet criteria for effective church mission work.
Acts 2: 1-4: The Spirit empowered them by transformation of self and a willingness to go and participate in others’ transformation. I suspect there is a need for the church to have a re-education of the dying process. In this process of re-education the Spirit of God can help us to prepare for our death and teach us how to become an active participant through mission in the dying process of others.

Retrieval

Jesus was the primary member of the trinity in this research project; he is both participant and active observer. Jesus’ death is recorded in such a way that it helps one realize the necessity of having a faith community present at one’s death. Jesus also models what it means to see the imago Dei in others who are sick, dying, or cast out. How Jesus responded to his and other’s death gives us a picture of methods of processing our mortality.

In Mark 8: 34-38 Jesus invites others to join him in an ongoing sacrificial and sacred venture for a greater good beyond self-grandiosity. When the church helped hospice patients and their families they were joining a sacrificial and sacred ministry setting. The caregiver and patient were already in a sacrificial and sacred mode. To care for one who is dying calls for some people to give of themselves in ways they have never experienced before. The time it takes is enormous; there may be night’s family members must wake three or four times to check on or respond to the patient. Being a caregiver can take a toll on other relationships, which is another type of sacrifice. There is financial cost to caring for the dying, involving the cost of day-time sitters, medicines, medical equipment and special types of food. Caregiving can be an enormous cross to bear. Therefore the church must be equipped to understand and journey alongside—even
willing to bear a cross with the hospice patients and families. There is something sacred about being a help to someone who seems helpless. When one looks into the eyes of a loved one and hears them say, “Thank you from the bottom of my heart,” it means a great deal. Or perhaps nothing is said from the loved one, yet you both are aware this care could not or would not be happening without a present, loving God providing strength from the Holy Spirit. The church must be sensitive to the sacredness of being involved with hospice patients and their families.

God’s will in Genesis 1:1-ff sheds light on how God brings order to disorder. God’s will is for the structures in place to move in harmony. Along those same lines is God’s will for hospice and church to work in harmony to help bring dignity, community, and meaningfulness to the sometimes chaotic business of dying and death. In Matthew 25 God’s will is the least to be cared for through relationship. God’s presence in this project is relationship building between church and hospice for more effective and faithful care to patients and their family.

In Bosch the researcher was introduced to the term Missio Dei (Bosch 1991, 10); God reveals God’s self as One who loves the world. The love of God undergirded the relational components in this project. In John 3:16 God is portrayed as the One who gives love and desires to establish eternal life as a good thing. Hospice and church together can help patients transition to eternal life more peacefully. God loved the world in spite of the world. The faith community must go into patients’ lives in spite of the chaos death and dying can bring.

Holy Spirit: In Acts 2 it was by the empowerment of the Holy Spirit the disciples received transformation. They were no longer constricted by their fear of death and
dying. With that liberation they were able to assist others in their transformation. In the same manner by the Holy Spirit the church participants were empowered to address their personal issues of myths about hospice, fears of death and dying, and accepting the call to offer volunteer ministry to hospice patients. With these changes the church was equipped to aid its members who were on hospice in a peaceful journey toward eternal life.

**Critique**

Some hospice patients and their families are experiencing end of life journeys without the comfort and support of a faith community. One reason for this is the lack of a cohesively-defined partnership between hospice and the church. The church in my context had not attempted to pursue an outreach ministry to hospice patients and their families. Therefore, the church was missing an opportunity to provide transformational acts of service, such as actively listening and sharing in some household/daily living chores. The church could have brought in sacraments and liturgy when appropriate and contributed greatly to the peace of the dying patient and their family. It was only after the project began were the participants sensitive to that need and able to bring gifts and graces with a deeper understanding of the death and dying process. Before the project Heartland Hospice had not explored the notion of collaborating with the church for the purpose of providing a more holistic care plan for their patients. They were receptive to providing staff and materials for the project after the researcher explained the project goal of creating a bridge between hospice and church.

**Suspicion**

The researcher suspected hospice patients who have spent many years separated from a faith community did not know how to reach out to a church or felt uncomfortable
with doing so. In the churches the researcher has pastored, prospective church-goers first come seeking the church and then the church attempts to maintain contact with them. In the researcher’s experience, it has typically not been the other way around—the church initiating the seeking. This makes it hard for shut-in hospice patients who are no longer capable of going outside, let alone church seeking.

The researcher had a hunch that separation between hospice and the church remained because members in the church believe myths about hospice. For instance, there is the myth hospice accelerates the dying process of patients. In addition, there is the myth that hospice is for people who do not have faith in God’s healing power. The researcher thought the church was slow to offer outreach to the dying because of its own unprocessed fear on mortality and a discomfort with the end of life setting. Nor was the church aware of how important help with activities of daily living would be to hospice patients and families, such as help around the house, sitting with a patient for socialization, and other tasks. The church did not understand how important the sacraments were to the patients and their families outside of the scope of the faith community setting.

**Understanding**

There was a need for the church to understand the “missiones ecclesiae” (Bosh 1991, 10) or missionary ventures of the church, that by its nature should be outreach to hospice patients and their families who need a faith community. In order for the church to faithfully achieve this they must enter into a partnership with hospice. This partnership with hospice will have to include reframing concepts of death and dying along with the role of hospice in the community.
Explanation

As long as church and hospice are without partnership, hospice patients and their families will continue to suffer without the help of the church. In some cases it is heartbreaking to watch as patients and their families struggle with activities of daily living along with ontological and eschatological questions and have no faith community as a guide. There is the story of John, who lived his 61 years of life separated from church. After John received a diagnosis of terminal head and neck cancer a chaplain from the hospital came in his room and led him to Christ. When John came on Heartland Hospice service he talked about his desire to be baptized in his home. On the Sunday the researcher baptized John, Mt. Carmel Christian Methodist Episcopal Church prayed over both the baptismal water and the first and only Bible John would ever own. John was baptized and it was a sacred event. John, his caregiver, the researcher, and the God of love were all present. John died less than two weeks after his baptism and his caregiver said John died with a confidence he would see his mother in death because they both were baptized. This researcher believed if Mount Carmel would have been present in John’s life as hospice volunteers, leading up to, during and after his baptism, John’s end-of-life journey would have been safer, less worrisome, filled with companionship and more fulfilling.

The church and hospice as a team could mean so much to so many, including church and hospice. The time was at hand for a serious dialogue to begin inside the church on mission to the dying patients and their families. This step took deep theological, social, and psychological reflection along with systematic education on death and dying.
The church is excellent in sharing the hope of the after-life. There have been various sermons describing the pearly white gates and the streets paved with gold. Yes, it is good to give hope; however, church has not taught about end of life preparation or process. For example, what does it mean to have a Do Not Resuscitate Order? How does one die with dignity when you need another to help you with all of your activities of daily living? As a church there must be preparation for the dying process and after-life. When the project participants began to wrestle with their own mortality from a theological, sociological, emotional, and physiological perspective, their ministry to hospice patients and families within the congregation became transformative and liberating.

As Dr. Paul Irion wrote, “Hospice functions in our contemporary pluralistic and secularized society, where not all patients and families are deeply rooted in a faith community” (Irion 1988, 42). Hospice is designed to be holistic; therefore, hospice should no longer neglect action towards partnership with the church. With the church seeking hospice and hospice seeking the church, enhanced care for terminal patients and their families will be achieved.

**Project**

Steps and Goals: A series of five dialogical sessions were designed for project participants, who included a pastor and hospice professionals to prepare church members to become hospice volunteers, and therefore establish a partnership with a hospice center in close proximity of the church. Within no more than three days the church group met with the researcher following to give feedback on the content of the previous session. In addition, the church group shared their feelings about death, hospice, and the information that had been given to them. These volunteers consisted of eight members—six females
and two males. This was also a time for the researcher to receive participant feedback on the project as a whole.

1. Session one: Pastor, church members, social worker, nurse, bereavement coordinator, and chaplain discussed “What is Hospice?” The session goal was to dispel the myths and learn facts about hospice.

2. Session Two: Pastor, church members, and medical director discussed end of life issues, preparation and choices. The goal of this session was to help members prepare for end of life decisions.

3. Pastor, project participants, chaplain, bereavement coordinator, and nurse discussed the dying process. The goal was to help the participants understand fears of death and learn Kubler-Ross’ five stages of grief.

4. Pastor, chaplain, social worker, nurse and participants discussed, “Stigmas attached to AIDS and other diseases.” The goal was for members to learn about universal precautions, increasing some participants’ comfort level with ministering to AIDS patients and other patients with communicable diseases.

5. Pastor, chaplain, volunteer coordinator and participants discussed “Church Mission to the Dying: The opportunity and need for volunteers.” The goal was to help participants realize the need for church outreach to hospice patients and their families.

**Desired Outcome**

The project was designed to assist the participants with the ministry challenges described above. The goals of the project were to educate and offer tools to assist participants to become willing hospice volunteers. The timeframe for each session was
scheduled for one hour. Each session was conducted by a professional person with experience in hospice care. The format for the educational sessions was five sessions in an open forum to educate and offer tools that would guide participants to a willingness to become hospice volunteers.
CHAPTER 4

Literature Review

There is a plethora of data in the literature about hospice and hospice care. However, there is a paucity of resources that support the importance of hospice centers and church/congregations teaming to provide care for those who are dying. This literature review shares selected material that supports the research conducted from a church and a hospice center who trained volunteers from the church to support patients under hospice care.

Review of Elisabeth Kubler-Ross’ Five Stages of Death and Dying

Kubler-Ross’ book On Death and Dying (1969 Macmillan Publishing, New York). In her Model of Coping with Dying patients, Kubler-Ross interviewed more than 500 dying patients to learn how people experienced the death and dying process. This model describes a five stage process by which people cope when diagnosed with a terminal illness or experience a catastrophic loss. In addition, her book brought mainstream awareness to the sensitivity required for better treatment of individuals who are dealing with a fatal disease or illness. According to Kubler-Ross, it is important to note that these stages are not meant to be complete or chronological. Not everyone who experiences a life-threatening or life-changing event experiences all five of the responses, nor will everyone who experiences them do so in the order in which they are presented. Reactions to illness, death, and loss are as unique as the person experiencing them. Not everyone traverse all of the stages or experience them in a linear fashion. Some steps may be missed entirely; others may be experienced in a different order. While some may be
re-experienced again and again and others may get stuck in one stage or another, Kubler Ross cites case studies to help bring clarity to the five stages of death and dying/grief process discussed below:

Stage 1. Denial: People tend to have the reaction “no not me,” “this can’t be happening to me.” “There has to be a mistake” (Kubler-Ross 1969, 38). Denial makes it easy for the mind to handle such devastating information.

Stage 2. Anger: Once in the second stage, the individual recognizes that denial cannot continue. At this point, the patient moves to stage 2 and begins to express “anger, rage, envy and resentment” (Kubler-Ross 1969, 50).

Stage 3. Bargaining: Kubler-Ross talks about the patients trying to bargain with the Divine.... Saying “God if you just allow me more time I promise......”(1969, 84).

Stage 4. Depression: In stage 4, sadness and isolation can be overwhelming to patients. The reality of the loss and impending death can take persons to a low place in spirit. It is in this stage that the person begins to disengage.

Stage 5. Acceptance: At this stage, individuals are at a point where they recognize the current state of their lives and resign to the time of departure.

Kubler stated that her book on death and dying was “not meant to be a text book on how to manage dying patients, nor is it intended to be a complete study of psychology of the dying” (1969, Preface). Kubler-Ross’s study and interpretation of the stages of death has been invaluable for professionals and lay alike. Her material through the years, have withstood the test of time. Therefore, though the material was published in 1969, this researcher wanted to go straight to the original source. The researcher agrees with Kubler-Ross and has journeyed as a hospice chaplain with a number of patients as they
traversed all five stages before they died. It was the opinion of the researcher and the hospice professionals to include the five stages in the project sessions. The five stages were helpful to the project participants.

The project participants (volunteers) experienced great benefit in learning the five stages of grief. It helped them to dialog and reflect on the fear of their own death. In each session, the participants were able to identify which of the five stages currently dominate their thoughts about death and dying. As a result, participant’s feelings of fear were apparent and were revealed in the discussions. This provided opportunity to develop tools for those fears.

The five stages also helped the participants offer care to the church members who were on hospice. Both family of the participants and non-family church members became hospice patients during the project. The project participants offered volunteer type care to each of them; the five stages of grief gave the participants a point of reference for identifying the emotional, psychosocial and spiritual state the patient was in. Learning Kubler-Ross’ the five stages of grief improved and added confidence to the project participants caregiving skills. This also helped them with their own fears of death and dying.

Miriam C. Berkowitz

Moses meets Kubler-Ross: the five stages toward accepting death as seen in the Midrash

Berkowitz brings to light and explains an ancient Midrash (rabbinic interpretation of biblical text, @ 400-600 CE) through the lens of modern psychological theory. The author describes Moses's reactions to his approaching death and points out that his
reactions follow closely the five classic stages of coming to terms with terminal illness. He brings to light and analyzes a text previously inaccessible to the non-specialist and notes practical applications for pastoral caregivers in dealing with the terminally ill in general. Berkowitz suggests reasons why Jewish patients may be particularly resistant to accepting death and how using this Midrash could offer a constructive model to approaching death. He is speaking from his experience as a chaplain using Midrash to help patients in their end of life journey.

The rabbis of the Midrash sense that each one of these five stages is natural and helpful in its own way. However, the order and relative length of each one may vary from case to case. Stages 2, 3, and 4 are manifested in a different order in the Midrash than in Kubler-Ross' research. The writer maps out the five stages of grief in the following manner: "Moses was a hundred and twenty years old when he died; his eyes were undimmed and his vigor unabated" (2001, 304). Moses is not ready to die. When God informs him that he will die soon, and without entering the land of Israel which he has labored so long to reach, Moses's first response was denial. However, when Moses saw that the decree against him had been sealed, he took a resolve to fast, and drew a small circle and stood therein, and exclaimed, "I will not move from here until Thou annulets that decree" (2001, 304). Kubler-Ross would call this stage depression, as the fasting symbolizes great sorrow, and the drawing of the circle, while elsewhere in Jewish sources is a way of protesting, literally represents cutting oneself off from other people and sitting for days in isolation. From depression, Moses moves immediately into anger. He cries out to God about the unfairness of the decree. "Is this the reward for the forty years" labor that I went through in order that [Israel] should become a holy and faithful people...?"
With only one-hour left, according to the Midrash, the stage of bargaining begins. Here we bring Moses's side of the dialogue, though the Midrash brings God's responses as well. Whereupon Moses said to God, "Master of the Universe, if Thou wilt not bring me into Eretz Israel (the Land of Israel), leave me in the world so that I may live and not die...? Said Moses to God, "Master of the Universe, if Thou wilt not bring me into Eretz Israel, let me become like the beasts of the field that eat grass and drink water and live and enjoy the world... Master of the Universe, if not, let me become in this world like the bird that flies about in every direction and gathers its food daily and returns to its nest toward evening; let my soul likewise become like one of them."

Moses said to God, "Master of the Universe, remember the day when Thou didst reveal Thyself unto me in the bush" remember the time when I abode on Mount Sinai for forty days and forty nights... I implore Thee, do not hand me over into the hand of the Angel of Death." Thereupon a Heavenly voice was heard saying to him, "Fear not, I myself will attend to you and your burial."

At that hour, Moses arose and sanctified himself like the Seraphim [angels], and God came down from the highest heavens to take away the soul of Moses, and with Him were three ministering angels, Michael, Gabriel and Zagzagel. Michael laid out his bier, Gabriel spread out a fine linen cloth at his bolster, Zagzagel one at his feet. Michael stood at one side and Gabriel at the other side. God said, "Moses, fold your eyelids over your eyes," and he did so. God then said, "Place your hands upon your breast," and he did so. He then said, "Put your feet next to one another," and he did so. According to Berkowitz, we see Moses coming to an acceptance of his death.
Berkowitz' material was very affirming, just as he used Midrash to apply the five stages of grief to the end of life journey of Moses, the researcher was able to recognize the five stages of grief in the end of life journey of Jesus. A portion of the biblical foundation of the project was based on the notion that the gospel writer of Mark understood the common human experience of death and dying which included the five stages.

In the next section of the literature review, the writings of George Kuykendall that do not agree with the five stages of grief will be explored.

George Kuykendall

*Care For The Dying: A Kubler-Ross Critique*

Christians are not... to delude people as to their capacity to master death. Christian care precludes giving them over to their own resources, in the fantasy that those resources may be adequate. Rather, Christian care for the dying will seek to sustain them as they suffer the ravages of living and dying. We must care for them as long and as well as we can, identifying their hurts and healing them if we are able, surrounding and enfolding them with reminders of the care that God bears toward them (Kuykendall 1981, 48).

In this article, the writer suggest that Kubler-Ross has significantly misunderstood dying persons' experiences and that she has stretched those experiences out on the Procrustean bed of her own philosophical and religious convictions. As a result, her approach tends to isolate dying people from others and to cut them off from the care they should receive. Furthermore, I believe that the Christian faith offers resources for a more substantial and helpful understanding of caring for the terminally ill.

Her starting point is impeccably Freudian, says Kuykendall. Denial, the first stage, is understood as a means of avoiding an idea or notion too painful to contemplate. She suggests that it serves to provide a breathing space during which the dying person may be composed and so mobilize "other, less radical defenses. Ordinarily, psychoanalysts view denial as a negative and regressive response; the patient should seek to recognize and deal with painful ideas, not deny them. But
the idea of one's own impending death is often so fearful that the mind refuses to acknowledge it. For the individual is experiencing a massive abandonment by every cherished thing the whole world is "leaving. The individual may, as a result, become depressed. Denial of the painful loss that initiated depression is often a symptom of depression (1981, 38).

(1) While Kubler-Ross believes that people are able to reflect on their own deaths and come to accept them, experiencing growth and creativity through dying, Christians understand human living and dying as fundamentally dependent on God. (2) In her paradigm, Kubler-Ross envisions dying people as fundamentally isolated. She views them, not as covenant partners, with whom one would maintain fidelity until they die, but as patients who need help to die acceptingly.

(3) Kubler-Ross' paradigm has achieved such great popularity because, at least in part, it enables people who are terminally ill to defend themselves against their fears of death. Professionals who care for the dying pay a fearful toll in caring for them and then lose them. By describing the regression and deterioration of dying patients as "development" toward "acceptance," Kubler-Ross legitimizes the emotional abandonment of the dying. For if individuals are surmounting fear and accepting, then professional helpers need no longer expose themselves to the pain of caring and then losing them; they are "making it on their own."

(4) In her first book, On Death and Dying, Kubler-Ross strongly criticized religion as a defense against the fear of death. I disagree with this writer regarding the misguided effort of Kubler-Ross. However I do agree with Kuykendallt, that Christians have a responsibility to provide care to the end of their life and not just guide the people towards hope for heaven. The writer did an excellent job in describing the fear element in death and dying "The world is leaving."
All three of the above writers expressed the fear involved in death and dying. The researcher believed that the fear of death and dying the writers discussed contributed to church members not connecting with patients in hospice. Therefore, their material was helpful in addressing the fear component of the project. However, neither speaks directly to hospice and church. Unfortunately, the material that does speak to hospice and church is very limited. The next section of literature review is church and hospice.

Paul E Irion.

Hospice and Ministry

Irion’s book was based in part on shared experiences of more than sixty pastors who have ministered to parishioners who were hospice patients. The author was actively involved in founding a hospice. He states the common ground of hospice and the church, one being care for the dying. He shares how hospice has helped him with addressing his own mortality. The researcher would echo that sentiment hospice has helped him also in accepting and processing death. The participants themselves have been better equipped in facing their death through association with hospice.

Irion states that because of the isolating nature of death and dying “some patients feel abandoned—by medical science, their friends and by God. Some people experience death as a great loneliness” (1988, 22). Irion believes patients that have a faith community and are active in their care plan can receive a sense of belonging that can combat the loneliness of death and dying. In the project, the researcher witnessed the positive effect of having a faith community involved in their care plan. It produced a tremendous impact for the good on the hospice patients in the local church. The potential impact a faith community can have on reconnecting those who have been disconnected
by the death and dying process are phenomenal. Through the presence of volunteers, a patient and family member can experience the incarnational love and acceptance of God.

A patient can work out their meaning in life when someone is present to listen to their life stories. It is important for those present to listen and not impose on the person who is dying. Questions designed to find meaning can be... for example “What it is like to die?” “Where is God in this process?” “Has my life been significant?” “How does God deal with people who have not done all they should.” “What is it like to be with God?”

Family members are more prone to ask, “Why her or him, while the patient asks, “why me?” Irion states that these questions have two dimensions. “On the one hand, they are expressions of a search for insight and on the other hand they are expressions of deep feelings of fear, guilt, anger or abandonment” (1988, 25). As the patient moves toward acceptance, one of the spiritual needs of the dying person is for affirmation of self-worth. “Self-worth is one of the essential components in quality of life” (1988, 28). The faith community must be present and ready to help through scripture reading and theological concept, but realize everyone does not want to take that route to process their death and dying.

According to Irion, the key to being with hospice patients and their family is being present and actively listening to the patient and their family doing other tasks that are needed. The aim of the visit is to come without an agenda, journeying with the patient wherever and whatever their spiritual beliefs are. The researcher agreed with and applied this author’s views on the benefit of a faith community involved in the care plan for a hospice patient and their family.
Brown stated that hospice caregivers walk side by side with patients and their families—neither ahead of them nor behind them—as they experience the complex interrelationship of the dance of life and of death. “True hospice pastoral care has to be liberating” says Brown (2009, 276). The researcher designed the project to assist the participants in experience liberation from myths about hospice, fear of death and dying and being blind to the need for active hospice volunteers in the congregation. According to Brown, there has to be liberating care offered, however, if one has not been liberated it can be difficult to share in another’s liberation.

“One must acknowledge that hospice care wears many faces, and that physical pain is often intertwined with (and intensified by) the hurt resulting spiritual, emotional, and/or psychosocial issues” (Brown 2009, 276). Therefore, to address this reality, caregiver’s work in interdisciplinary teams composed of nurses, social workers, chaplains, volunteers, doctors and administrators. In this model, there is no hierarchy; each team member is equally valuable for the patient and family care. Pastoral care can come from any team member and should be considerate of the patients and families faith system. The author believes care that hospice team members give is linked to justice and compassion as found in the biblical text Micah 6:8-9 …“He has told you, O mortal, what is good; and what does the Lord requires of you but to do justice, and to love kindness, and to walk humbly with your God?”
Joan Webber

Don't let them Die Alone

Joanne Webber, widow of beloved theologian Robert Webber, notes the irony of "The people most likely to call on a hospice chaplain are non-Christians," she says (2009, 19). "Because Christians tend to be surrounded by their family and friends, it might actually intimidate the hospice person. You would end up giving your testimony to them" (2009, 19). "The church is not to miss this chance to serve those whose worth is no longer about productivity but primarily, and simply, about bearing God's image. Given that the number of hospice patients will rise as the boomer generation ages and hospice care becomes a normal part of dying in America. Christians ought to be at the forefront of providing this ministry of presence in years to come" (2009, 19). Those with the heart for spiritual care can complete most chaplaincy certification programs within two years. And lay members, though not always able to interact with patients, can volunteer at hospitals and nursing homes and visit neighbors to meet practical needs and assure families they are not alone. Webber advises:

Instead of requiring the weak and hopeless to seek us out, we should be seeking them out, bringing with us the presence of Christ. And, if sensitively timed and led by the Holy Spirit, we may be asked to speak of the "reason for the hope that you have"—even in the face of death. It is the unique Christian hope in the Resurrection that should compel us to share it with those who need it most (2009, 19).

The researcher would agree with Webber that the imago Dei in humanity is more important than ones productivity. Webber's rationale of the church seeking people in the dying mode was important to the fifth and final session of the project. In that setting the participants affirmed they would seek out the dying and not wait for them to seek out the church.
Contemporary society’s perception and experience of death are undergoing basic revision. No longer has ‘denied’ and concealed, death become an urgent and even a fashionable topic. New life-extending techniques, court cases (e.g., Quinlan), Kubler-Ross’ stages’ of dying, the hospice movement, and a plethora of publications have brought death into the limelight” (Fassler 1999, 231).

There is much in contemporary life, which suggests that our own era is a watershed regarding attitudes toward death and dying, and that the place of the dying and their families has been reinserted into our society. The reasons for this change are not only the many provocative studies and practical casework from the 1970s and early 1980s alluded to above, although they were certainly of central importance. AIDS has brought an activist stance for the dying, and offers impetus for memorial services planned out by the dying themselves, who, afflicted with such a disease, often have time for preparation and reflection. The AIDS quilt has inspired communal celebrations of those who have recently died, with displays in public places, from airports to the unfolding of the massive sections of the entire quilt in the capital (Fassler, 1999). Fassler suggests:

The Vietnam Memorial in Washington, D.C., provokes intensely emotional experiences for survivors of the war, and allows for the remembrance of individuals and groups simultaneously, promoting healing through common remembrance. Public ways of remembering the Holocaust through museums and other displays focus on the unimaginable numbers of victims, while celebrating the lives of particular men, women, and children as well (234-235).

Zoba, Wendy Murray.

[Dying in peace] in Birmingham, an innovative program combines hospice care, traditional medicine, and faith to comfort the terminally ill.
According to Zoba, despite the soon-to-double number of aging Americans, most don’t want to think or talk about how to die. There are now 40 million elderly people in the United States. In the next 30 years, "with the aging of the baby boomers, that number will double. One third of those 80 million deaths will involve a chronic illness of some sort. Every chronic illness will require decisions, either on the part of the patient or the family. If present trends persist, most of these people will not have thought through end-of-life questions. According to a national survey taken by the National Hospice Federation in April 1999, Americans are more likely to talk to their children about drugs and sex than about how they want to die. Even so, 50 percent of Americans overwhelmingly say they will rely on family and friends to make end-of-life decisions.

Nearly 80 percent of Americans do not think of hospice as a choice for end-of-life care; 75 percent do not know that hospice care can be provided at home; fewer than 10 percent know that hospice provides pain relief for the terminally ill; more than 90 percent of Americans do not know that hospice care is a fully covered Medicare benefit. This is a communication challenge.

40 percent of the 258 doctors surveyed said they "would knowingly give inaccurate estimate of survival time, even if the patient had specifically asked for a frank prediction. Most doctors erred on the side of optimism" (Chicago Tribune, June 19). But beyond institutional resistance, the pragmatic youth-oriented culture we live in also works against having this conversation.

In the project preparation the researcher found it important to address the lack of awareness of hospice and the services it provides. It was very important to the success of the project to dispel the myths and educate the participants on hospice. Therefore, session
number one was designed to provide an overview of hospice and to foster any questions the participants may have had.

Daniel Johnson

*Let's Talk about Death*

Daniel Johnson explains:

Although the reasons for reticence are complex, our society's general reluctance to embrace the end-of-life conversation is worth exploring—especially in light of the health-care crisis. Some claim that this reluctance is a result of America's denial of death: "Others will die, but not me." Some describe our society as 'death-defying.' We're fighters. We never give up. Americans 'wage war' with death. Just look at a headline like this one referring to actor Patrick Swayze: ‘Swayze Loses His Battle with Cancer' (2010, 10).

Defying death is not cheap. In its quest to restore youth and cure disease, the U.S. spends billions of dollars each year on medical technologies. While we have made great strides in treating serious illness, the progress comes at a great cost. In 2007, $2.2 trillion—16 percent of the nation's gross domestic product—was spent on health care. Despite this staggering sum—the highest per capita spending in the world—the United States ranks 27th in the world in life expectancy and 37th in overall quality of care as defined by the World Health Organization.

As a physician, says Johnson, “I've learned about the challenges of the advance-care planning process from my patients and their families. Predicting one's preferences ahead of time is difficult. Many patients simply don't know what they would want in the event of incurable illness. Some respond with ‘Life support?’ Well, I suppose it depends. . . . Ask me when I get there" (2010, 10). Others prefer to defer life-and-death decisions to their families: "My family will take care of that. They'll know what to do" (2010, 10).
But studies tell us that our loved ones often struggle to determine "the right thing to do," and many report feeling overwhelmed with stress and guilt (2010, 10).

Talking about the end of life is often uncomfortable. Why think or talk about something as unpleasant as our own (or our loved one's) death? Why not think about happier things—and cross that difficult bridge later? Patients have taught me, however, that later is often too late.

Many of us don't know how to talk about death. It's not that we're denying our mortality, or that we're afraid of expressing emotions to our loved ones. We simply don't know how to start that conversation. No one has taught us the words or the format for such a discussion. We don't have a safe space, we don't know the right time—so we don't have the conversation.

The researcher agrees with Johnson. In session two of our project, the Medical Director of Heartland Hospice came to our church and presented lessons on the importance of and tools for having end of life discussions. As a result of the second session, many project participants completed a South Carolina Health Care Power of Attorney.

Geweke, Deborah L

"Hope in hospice? Accompaniment of the Spirit through life's journey."

According to the biblical witness, whenever the community of faith gathered God's holy presence was actively there. One might envision this proximal relationship with God to be a thing of the past, a mere remnant from the time in which God walked in the garden or spoke from bushes or, at least, last realized in the flesh and blood of Jesus of Nazareth. But "distance" from the divine is not a uniquely contemporary problem, as is
evidenced in particular by the issues confronting the late first-century community of John the Evangelist.

Among the four canonical Gospels, John is perhaps the most pneumatological. Perhaps this is a function of divine distance. The last canonical Gospel to be written was the Gospel of John, in grand literary and theological style addressing the needs of a community that is distanced from the earthly presence of God in the person of Jesus by as much as sixty to seventy years. Regardless of rationale, the author of John develops a pneumatology that clearly enables distant communities of faith (separated from Jesus particularly by time) to connect to Christ in such a way as to comprehend God as a living and life-giving reality.

Unique to the Fourth Gospel, perhaps due to the distant circumstance of John's community, are the Farewell Discourses of Jesus (John 14-17.) Within these three chapters (concluding with Jesus' High Priestly Prayer in chapter 17) Jesus prepares his disciples for his departure from them. Within those preparations is an element likewise unique to John—the Paraclete (or Advocate).

The anointing of the Holy Spirit was powerfully active as a transforming agent all though the preparation for and execution of the project. All who had the opportunity to be involved in this project informed the researcher their lives had changed in some way as a direct result of the project.

The literary review was invaluable for the researcher. There was a paucity of resources that related directly to hospice and the church. This fact informed the researcher of the value this project has for training hospice volunteer and developing hospice ministries within churches around the globe.
CHAPTER 5

The Project: Steps and Goals of Preparing Church Members to be Hospice Volunteers

Some hospice patients and their families are experiencing end of life journeys without the comfort and support of a faith community. One reason for this is the lack of a cohesively-defined partnership between hospice and the church. The church in my context had not attempted to pursue a volunteer outreach ministry to hospice patients and their families. Therefore, the church was missing an opportunity to provide transformational acts of service, such as actively listening or sharing in some household/daily living chores. Through the process of becoming hospice volunteers the church could bring in its sacraments and liturgy when appropriate and contribute greatly to the peace of the dying patient and their family.

The researcher suspected hospice patients who have spent many years separated from a faith community did not know how to reach out to a church or feel uncomfortable with doing so. In the churches the researcher has pastored, prospective church-goers first come seeking the church and then the church attempts to keep up with them. It usually is not the other way around where the church initiates the seeking in the researcher’s context. This makes it hard for some patients who are no longer capable of going outside, let alone venturing out to seek for a church to become affiliated with.

The researcher had a hunch that separation between hospice and the church remained because members in the church believed myths about hospice. There was the myth hospice accelerates the dying process of patients. In addition, there was the myth that hospice is for people who do not have faith in God’s healing power. The researcher
also suspected the church was slow to offer outreach to the dying because of its own unprocessed fear of death and a discomfort associated with not having a sense of what to say or do in the end of life setting. The researcher believed the church wasn’t aware of how important help with activities of daily living was to a hospice family; help around the house, sitting with a patient for socialization and other tasks. He didn’t think the church understood how important the sacraments are to the patients and their families outside of the scope of the faith community.

One of the most difficult realities that theologians and health care professionals face is that some patients will die. Although we cannot change this fact, we can have a significant and lasting effect on the way in which people live until they die, the manner in which the death occurs, and the enduring memories of that death for the families. In the past four decades there has been a surge of interest in the care of the dying, with the emphasis on the settings in which death occurs, the technologies used to sustain life, and the challenges of trying to improve end-of-life care. The concept of hospice is considered by many to be the “gold standard for care for those who are approaching the end of life.” Hospice, which originated in Great Britain, best addresses the needs of those whose death is imminent.

Hospice is a coordinated program of interdisciplinary care and services provided both in the hospital and in the home to terminally ill patients and their families. The needs of patients with terminal illnesses are best met by a comprehensive multidisciplinary program that focuses on quality of life, palliation of physical symptoms, psychosocial and spiritual support for the patient and family when death is inevitable. Hospice care can be provided in several settings such as a free standing based community
hospital or home based setting. However, hospice care is usually delivered at home when at all possible. While individuals who are hospitalized may also receive spiritual care, they often miss the opportunity to be connected to the church and or church family. In many cases, there is no “church” link between patients undergoing hospice care in hospital or hospice settings. Therefore, the purpose of this project was to train volunteers from a church environment, in close proximity to the hospice center, to provide care to patients who are admitted into hospice care. The program is presented as follows: A series of five dialogical sessions were designed for project participants, who included a pastor and hospice professionals to prepare church members to become hospice volunteers and therefore establish a partnership with a hospice center in close proximity of the church. The church group met with the professional hospice personnel within a three-day period before each session to share the content of the previous session. In addition, the church group shared their feelings about death, hospice and the information that had been given to them. These volunteers consisted of eight members: six females and two males, including the pastor who was also a male. This was also a time for the researcher to receive participant feedback.

The preparation for the project started with the researcher holding a series of Bible studies on the subject matter of bereavement and death and dying with the congregation. This provided a safe space for potential participants to discuss their concepts of hospice, their fears of death and dying and reflect on help persons need in the death and dying process. The researcher also preached a series of sermons from the New Testament passion narrative. Utilizing Dr. Kubler-Ross’ five stages of death and dying
within a biblical model highlighting Jesus Garden experience. This process helped the researcher connect with participants for the project, and develop research questions.

The researcher held meetings with the administrator of a local hospice to discuss the possibility of staff holding information sessions with project participants. Once the researcher received approval from the administrator to have hospice staff meet with project participants, meetings were set up with the various disciplines of the hospice staff (Medical Director, Social Worker, Nurse, Bereavement Coordinator, Chaplain and Volunteer Coordinator). In these meetings an action plan was devised to address the participant’s myths about hospice, unprocessed fears of death and dying and seeing the need to become hospice volunteers. The researcher decided to provide informal feedback sessions for the participants and researcher to follow each session with the hospice staff.

Session one consisted of social worker, nurse, bereavement coordinator, and chaplain sharing with the project participants their roles in hospice care. In the first informal feedback sessions the participants were given a survey. Following each formal session the participants and the researcher gathered. The participants shared their thoughts on the session and the application of the information they received. In session two the medical director had a conversation with the entire church. There were question and answer periods. The church members received handouts on end of life challenges and healthcare power of attorney forms. Session three entailed chaplain, bereavement coordinator and nurse discussing with the participants, Dr. Kubler Ross’ five stages of death and dying concept. The participants received a handout on the five stages of death and dying. Session four involved the chaplain, social worker, nurse and participants discussing stigmas attached to AIDS and other diseases. The participants received a hand
out on universal precautions. The fifth and final session consisted of a volunteer coordinator talking with the project participants on hospice patients and their families need for volunteers. The members received applications for hospice volunteer.

**Sessions and Feedback**

1. Pastor, project participants, social worker, nurse, bereavement coordinator, chaplain to discuss “What is Hospice?” The goal of this session was to dispel myths and learn facts about hospice.

The initial meeting consisted of six (6) members from The Mount Carmel Christian Methodist Episcopal Church. This group agreed to meet with staff from Heartland Hospice to become acquainted with the hospice environment. The language as well as all of the hospice information was new to the church members. This was a major step for the project participants to begin assessing themselves if they wanted to become a hospice volunteer. At the inception, the chaplain/pastor distributed a questionnaire (appendix A). The hospice chaplain also served as pastor of the Mt. Carmel Christian Methodist Episcopal Church. Ironically, this meeting was held at the Unity Funeral Home in Anderson, South Carolina. The hospice staff that attended the meeting included a nurse, social worker, bereavement coordinator and the chaplain. After the introductions the nurse distributed a Heartland brochure and the Ten Myths of Hospice (see appendix B) to each church member.

The team began to describe hospice care as follows:

- Hospice is considered to be the model for quality, compassionate care for people facing a life-limiting illness (six months or less) or injury.
Hospice and palliative care involve a team-oriented approach to expert medical care,

- Pain management expressly-tailored to the person’s needs and wishes.
- Emotional and spiritual support is also provided for the person's loved ones.
- The focus of hospice care relies on the belief that each person has the right to die pain-free, with dignity, and that their loved ones will receive the necessary support.
- Hospice focuses on caring, not curing and, in most cases, care is provided in the person’s home.
- Hospice care is also provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.
- Hospice services are available to patients of any age, religion, race, or illness.
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Hospice care is a family-centered approach that includes at a minimum, a team of doctors, nurses, home health aides, social workers, chaplains, counselors, and trained volunteers. This team works together focusing on the needs of the total person to include their physical, emotional psychosocial and spiritual needs. The major goal of hospice is to help keep the dying person as pain-free as possible, with loved ones nearby until death. The hospice team always develops a care plan that meets each person's individual needs to include pain management and symptom control. In this session, each staff member
shared significant details about their discipline and the other disciplines not present, to include medical director, nurses, social workers, and nurse’s aide: The following is a synopsis of the discussion:

**Medical Director:** The Medical Director is the head of the medical team and must be knowledgeable about the medical and psychosocial aspects of hospice care. The Standards provide that the Medical Director reviews, coordinates, and is responsible for the management of clinical and medical care of all patients. The Standards further state that the Medical Director’s expertise in managing pain and symptoms associated with the patient’s terminal illness is necessary, regardless of the setting in which the patient is receiving services, to ensure that the hospice patient has access to quality hospice care. The Standards explain that the Medical Director’s responsibility includes, but is not limited to: a. Serving as a consultant with the attending physician regarding pain and symptom control as needed; b. Serving as the attending physician if designated by the patient/family unit; c. Reviewing patient eligibility for hospice services; d. Participating in the review and update of the Plan of Care for each patient at a minimum of every 14 calendar days, unless the Plan of Care has been reviewed/updated the attending physician who is not also the Medical Director or Physician Designee.

**Hospice Nurse:** Hospice nurses perform many traditional nursing duties such as observing, assessing, and recording symptoms, and they still work closely with physicians, administer medications, and provide emotional support. Hospice nurses have a particularly tough job because, from the outset, they know that the patient for whom they are caring is terminally ill. The medications that hospice nurses administer and the symptoms they record aren’t intended to aid a patient in his or her recovery, but rather to
make his or her remaining days as comfortable as possible. Most of the nurse’s duties involve minimizing pain. Although being a nurse of any kind is very difficult, dealing every day with a dying person requires an exceptional temperament, one that embodies great caring, patience, and resolve. Hospice care is what is known as comprehensive palliative medical care, i.e., treatment to reduce pain and other troubling symptoms as opposed to treatment to cure. The hospice doctrine states that terminally ill patients have the right to spend their last days in the comfort of their own homes, with their families, and hospice care provides professional medical care as well as supportive social, emotional, and spiritual services to accomplish this. The hospice nurse’s duties fall somewhere in between all of these ideals with emphasis on medical care. Because they essentially act as home-care nurses and spend several hours a day with their patients in their homes, they become emotional caretakers as well. Patients can be any age, race, or creed, and it can be especially trying on hospice nurses to attend to patients who are as young, or younger than they are. Hospice nurses coordinate the care of every hospice patient through an advising physician, provide direct patient care, evaluate the patients’ conditions, and serve as the liaison between families and physicians. A hospice nurse may also work with a patient’s social worker, home-care aide (who may do housework and provide hygienic care to a patient who is incapable of bathing and caring for him- or herself), and physical, occupational, or speech therapist.

**Nurse’s Aide:** The Hospice Aide provides personal care to patients in their homes under the general direction of a registered nurse. Most patients receive hospice care in their own home, although it can also be provided in other facilities as well. Many times, the hospice aide spends the most direct patient care time with the patient and the family
and can contribute very beneficial information to the team during the development and update of the patient plan of care. Hospice aides must report changes in the patients' medical, nursing, rehabilitative, and social needs to a registered nurse. A Hospice Aide knows and understands the Hospice Philosophy, assists the client or family in the achievement of physical and emotional comfort according to the plan of care, and assists the patient in coping with terminal care.

Social Worker: The first responsibility of the social worker is to evaluate the needs of the patient and their family upon entering the hospice program. Going forward the social worker represents the individual/family's wishes at every hospice team meeting. At the initial evaluation the goal is to identify where each of the patients and their families are emotionally. Using this as a starting point, social workers then join them on their journey and continue along at their pace. It is not the social worker's job to impose any particular agenda. They are there to support the patient and their family's wishes, and address their concerns be it financial, emotional or ethical. Additionally, a social worker's responsibility is to be aware of and sensitive to any social, cultural or religious ideals regarding the end of life process that is specific to each patient. During the hospice process families often struggle with self-care. Social workers help them realize that they need to first take care of themselves so that they can be healthy, strong and able to then care for their loved one. Foremost, social workers are there to help support the patient and family in the areas of emotional care. For those patients or family members experiencing tremendous emotional grief, social workers may act as a grief counselor or hospice therapist. In some cases where there is a need for additional psychological counseling, social workers will put the patient or family member in touch
with a licensed therapist specializing in this area. Understanding the family dynamics surrounding the patient is an important role of the social worker. Oftentimes family members may disagree on the end of life decisions of their loved one. In these cases, social workers can help educate family members regarding any misconceptions or dilemmas they may be facing during this stressful time.

**Bereavement Coordinator:** Bereavement Care is offered to grieving family members by hospice before, during and for 13 months following the death of the patient. The goal of hospice bereavement care is to enable family members to receive support throughout the grieving process. Bereavement services are also offered to members of the community at large. Bereavement Coordinators facilitate support groups as a means of healing. They regularly contact family members and continually make assessments regarding their care plan. There are times before a patient dies that Bereavement Coordinators offer anticipatory grief counseling.

**Chaplain:** A hospice chaplain's primary responsibility is to provide emotional and spiritual counseling to patients and their families. Other duties may include submitting written reports on patient interactions and acting as liaisons between members of the clergy and hospice patients. Chaplains do not replace clergy members but rather are there to offer further support and communicate the needs of the patient. Additionally, chaplains provide bereavement services, including phone calls, visits and memorial services to family members upon the death of a patient. A major part of chaplaincy is sitting and listening to patients and their families.

Chaplains can act as a go between patients and their local pastors or they can become the family pastor for patients without faith community ties. Chaplains perform
the sacraments such as communion and baptism. Chaplains also offer spiritual care to
other hospice team members. Another ministry duty of the chaplain is to perform a
spiritual care comprehensive assessment which includes the degree of support for the
patient and family ranging from high, medium or low in the following areas: family,
friend, community groups, and religious groups. Using the assessment, an attempt to
gauge the level of preparedness for death of the patient was made. During the assessment
the patient, family and chaplain also discussed end of life matters such as advanced
directives, do not resuscitate and funeral arrangements. This is a method of identifying
areas of support that will be needed in the spiritual care of the patient and family. The
chaplain has the responsibility to provide the sacraments to the patient and family. This is
very important because some patients are not able to leave the house because of their
condition. Along with that some family members, because of the demand of caregiving,
cannot connect with their church or any church.

Volunteer Coordinator: Volunteer coordinators teach recruits about hospice
volunteer duties and ensure that the duties are performed adequately. They create a job
description and ensure that the volunteer understands it and completes the duties listed.
They also show volunteers how to handle sensitive subjects, such as the death and dying
process; the emotions of the patient and her/his loved ones; and financial and social
issues. The coordinator monitors the volunteers and provides correction where needed.
The volunteer coordinator creates and maintains schedules and ensures that they are
followed. He/she works with hospice staff and administration to determine where
volunteers would be best utilized. The volunteer coordinator shows volunteers how to
document their work and files those documents so the hospice agency can show exactly
what work was performed and when. Proper record keeping also documents the training each volunteer received and any testing completed. Volunteers often help by visiting the patient, performing light duties and comforting the patient and his family. A hospice volunteer coordinator ensures that patients and volunteers work together effectively.

Following the introduction the dialogues about the myths of hospice were started. Some church members expressed their surprise of all that hospice care covers. The members had questions surrounding eligibility process. The hospice team walked the group through the process. What is initially there is a referral from a physician for hospice evaluation and admit if possible, then a RN will assess the patient in consultation with the medical director for hospice eligibility. If the patient is determined to be eligible for hospice, the physician will prescribe medicines and treatment necessary for the patient. Other disciplines will visit the patient and make their contributions to the plan of care. The team will make decisions on frequencies of visits. The patient has 24/7 access to medical service from a nurse and a physician. Every fourteen days there is a team meeting to assess each patient and family condition and to reassess the care plan.

At the time of death hospice is notified and a nurse along with other team members will immediately respond by going to the patient’s bedside. The nurse will pronounce the death and contact the funeral home for the family. Because the patient was on the hospice service, the coroner will be notified, but will not have to come to the location. The hospice team will remain at the home until the mortuary arrives and takes the body away. From the point of death, hospice will provide care for family members and other caregivers for thirteen months after the death. The bereavement coordinator will become involved at this point. They make phone calls and visits to the bereaved and
offer other services like support groups, mail educational information regarding the grief process and help in the grief process.

The Church Participants Responses: This meeting lasted for ninety minutes and at the end, one of the church members commented, “Now I have a face to put with hospice.” The researcher’s observation revealed at the end of the session both the church members and the hospice team appeared to be more relaxed with each other. The members had never had this much firsthand information on hospice. The members and the hospice team were agreeable to continue in participating in this project.

The following Sunday morning the six who agreed to participate, along with the researcher, met before their worship service. The researcher distributed survey questions to the members (appendix B) and informed them they would receive the same questionnaire at the last session. The researcher asked the members if they wanted to share any impressions or make comments about the meeting with the staff from hospice. The members were open about their experience. The entire group was astonished at how many of the ten myths they believed. Participants expressed until the meeting with the hospice staff, that they thought hospice was a hospital type building where people were sent to die. Another participant commented this was the first time they had discussed death and dying in such detail and it was frightening. The entire group seemed surprised at the importance of spirituality in the care hospice offers patients. The members filled out the questionnaire and collectively agreed to continue in the research project.

2: Project participants, pastor and Heartland Hospice Medical Director discuss End of Life issues: preparation and choices. The goal of this session was to help members prepare for end of life decisions.
The Medical Director of Heartland Hospice was the speaker for the 11:00 a.m. Sunday morning worship service. Rather than standing, he sat in a chair in front of the congregation. He began his presentation by saying, “Let’s do this as if you were in my office.” He discussed advanced care planning for end of life care (see appendix C). He also shared the importance of having conversations within families and your healthcare providers. Further, he shared a case study from his practice of families that did not have end of life discussions and the struggles they encountered. One case in particular involved a fifty-one year old woman that was married and became terminal and unresponsive. She was living only by life support. When the medical team approached the family with the option of allowing the patient to die a natural death by removing the breathing tube, the family crisis increased. The husband was uncertain of what action to take; the children were divided in what their mother would want. The outcome was a big family argument at the patient’s bedside.

The physician urged the membership to have the discussion with family and important persons in their lives. He also offered suggestions on how to carry out the conversation (see appendix C). Use questions like; “What makes your life worth living?” “How would you like to spend your last days?” “What are your spiritual beliefs that might affect treatment choices?” He told the congregation that it is important to identify a decision maker willing to be involved in all end of life discussions. A member asked the physician if the decision maker has to be a family member. He stressed the importance of completing a Healthcare Power of Attorney (Researcher passed out South Carolina Healthcare Power of Attorney forms to church members prior to start of service, see appendix D). This form allows a person and their designee to have it in writing who will
make health care decisions if the patient is incapable of making their own decisions regarding medical treatment. This person does not have to be a family member as sometimes family members may not be the best choice. The doctor said it is important for the patient and proxy to be informed on the definition of key medical terms, with the benefit and burdens of treatment. Life support may only be short term and any intervention can be refused. Recovery cannot always be predicted. The conversation should focus on what kind of care is desired rather than what should be withdrawn. Topics should include: pain management, artificial nutrition and hydration, Cardiopulmonary resuscitation (CPR), mechanical breathing machines, blood transfusion, dialysis, antibiotics, HAART (HIV medication) and other medication. The doctor also informed the congregation regarding what a Do Not Resuscitate Order (see appendix E) means. This is a physician’s order signed by the patient or their representative that informs all emergency personnel who may be called to render assistance to a patient, that they have been diagnosed as terminally ill by their doctor and do not wish to extend their life. He further explained this means if a patient’s heart stops, there would be no attempts to bring them back to life. The medical director also made it clear that a DNR does not mean the medical team will stop treatment while the patient is alive. For example, if a patient has a urinary tract infection, that person would receive medication for the infection.

The medical director told the congregation there have been studies that suggests “Spiritual or religious strength sustains many people in times of distress. The medical director said many people want to keep their loved ones on life support for reasons of faith “God can do miracles.” He stated, however, the miracle comes when or if you take
the patient off life support. While a person is on a ventilator it is no miracle it is mechanical. When a patient is off the ventilator or artificial apparatus, that is when the Divine providence is manifested. One of the members spoke up and said I never thought about it like that but it makes sense what you have said.

The doctor spoke more specific about the importance of spirituality in the African Americans’ end of life experience. For the African American patients spirituality provided emotional and psychological support for the terminally ill in a high percentage (see appendix F). Based on four bedrock beliefs:

1. The providence of God and the Divine plan for each person’s life.
2. Intimate relationship to God expressed through prayer.
3. Almost all patients were willing to share their beliefs during long bedside interviews.
4. Willingness to share indicates that physicians can learn and validate the patients’ spiritual source support.

The physician informed the congregation that many studies show African Americans prefer more life support at the end of life. African Americans compared to Whites are less likely to discuss end of life care with medical staff, report lower in depth conversations with clinicians and are more likely to feel talking about death may bring death closer (see appendix F). Some members were nodding their head when the doctor said African Americans believe if you talk about death it draws near. He said in closing, if it is possible for this church to participate with hospice through volunteering in the care of patients and their family, it would be for the good of everyone. During the course of the doctor’s sixty-minute presentation some members walked out. After the presentation
various members thanked the medical director for his time and effort in helping them prepare for the end of life.

2A. The following week the participants and the researcher met before Bible study to discuss the doctor's message. The feedback was very interesting. The group overwhelming said they had never engaged in the subject matter of end of life before in a Sunday service. One member stated she doesn't get that much direct time with her own physician. One member shared it was frightening for her to discuss dying openly. When probed she admitted she fell into the category “Feel talking about death may bring death closer.” She also disclosed that fear has hindered her from reaching out to family and friends that were dying. The researcher believes her openness stimulated others to talk about their fears and insecurities. The researcher affirmed her willingness to participate in the project even though it had been uncomfortable for. They talked about how facing ones fears of death can be therapeutic. The participant was encouraged to reflect on when she first remembers her fear of talking about death. The researcher advised, as her pastor, that he would be available for a more private session on her fear. One person shared her hesitation about offering ministry to hospice patients and their families as she never knows what to say to the dying or the bereaved person. The group agreed with her, they had experienced the feelings of inadequacy when speaking with a person dying or bereaved. The researcher told them listening is just as important if not more important in the dying and bereavement process. He assured them there is no magic formula because grief affects people differently. He indicated that the further they were to get into the project, the more they would learn and the more comfortable they would become.
The project group informed the researcher that some of the members of the congregation who were not a part of the project group found it difficult to engage the Dr. because of the novelty of having a physician talk about end of life issues during a Sunday service. The entire project group thought the medical director’s presentation caused them to think broader about end of life care. Three of ten said they filled out the South Carolina health care Power of Attorney.

3. Pastor, project participants, chaplain, bereavement coordinator and nurse to discuss the dying process. The goal was to help the participants share and understand fears of death and learn Kubler Ross’ Five Stages of Death and Dying.

This meeting took place on a Thursday evening at the home of a social worker for Heartland Hospice. The social worker’s home provided a comfortable noninstitutional atmosphere. The chaplain began relating stories of patients expressing their feelings of death and dying. The story was about a patient who was dying from Chronic Obstructive Pulmonary Disease. The chaplain shared the patient talked about how he was in denial when he was first diagnosed. His denial led him to three different doctors, only to receive the same diagnosis. Then the patient talked about how he prayed and asked God for more time to see his son grow older and have a family. He referred to it as his bargaining with God. The next stage the patient took was depression. He told the chaplain he went weeks without a meaningful conversation with any of his family. He said “All I could think about was the fear of dying and all I would be leaving and never see again.” Then his anger at God for letting him get sick and his anger at his family for being well came through. He told the chaplain that he was mean to his wife and would be short with his son routinely in a day. This patient told the chaplain finally one day in the middle of
struggling to get his breath his wife came in and helped him sit up and connect to his oxygen. He then had what he called a revelation. He realized his life and his family had been amazing. He also found a peace that death could be a relief from the constant struggle to breath. From that day forward the patient had an acceptance of death that for him, made each remaining day of his life special. The chaplain shared the patient died three weeks after telling his story. One of the participants talked about her experience with her father dying and how he went through different moods. Another participant stated she saw similar behavior’s in her husband in his dying process as the patient in the chaplain’s story.

The social worker told the group the stages exhibited in the patient’s story and their loved ones are common in persons who are dying. She began talking about Dr. Elisabeth Kubler Ross’ book On Death and Dying (Ross 1969). The book outlined five stages of grief in the dying process (see appendix G).

1. Denial. People tend to have the reaction no not me, this can’t be happening to me. There has to be a mistake.

2. Anger. When a person has lived in denial all that they can feel is “anger, rage, envy and resentment.”

3. Bargaining. Kubler-Ross talks about the patients trying to bargain with the Divine, “God if you just allow me more time I promise.”

4. Depression. In this stage sadness and isolation can be overwhelming to patients. The reality of loss and impending death can take persons to a low in spirit.

5. Acceptance. At this stage, individuals are at a point where they recognize the
current state of their lives and resign to the fact that this is their time of departure.

The nurse helped the participants see and name the five stages in the patient’s story the chaplain told. The participants appeared very pensive as the 90-minute session was closed.

3A. The following Sunday before service the researcher and the participants spent time together dialoging about the time spent with the hospice staff. The participants informed the researcher they left the last session with the hospice team thinking of their own mortality. One participant stated how he has been in denial regarding his own death, others agreed. The same member stated he was grateful for his participation in the project. He has found himself facing his fears and the sessions have provided him with a better understanding of the dying process. Another participant said the project information is helping her relate to her elderly mother that is ill. She asked the researcher for information on getting her mother on hospice. Another participant asked the researcher to speak with a church member whose father is ill about hospice. The researcher facilitated the following day a hospice admission for both referrals.

4: Pastor, chaplain, social worker, nurse and participants to discuss “Stigmas attached to AIDS and other diseases.” The goal was for members to learn: about universal precautions that will help them feel comfortable ministering to patients with AIDS and other communicable diseases.

The nurse started the session with defining universal precautions to prevent the spread of infectious diseases as the participants followed along from the hand out (See appendix H). The nurse informed the group that it is important to take precautions to
prevent the spread of infection and disease when working in healthcare. One must protect oneself and the people they work for. Many diseases can be passed from one person to another, some more easily than others. One risk that healthcare workers face is exposure to blood borne pathogens. Three common blood borne pathogens are the Human Immunodeficiency Virus (HIV), Hepatitis B (HBV) and Hepatitis C (HCV). A vaccine is available to provide immunity against Hepatitis B. There is no approved vaccine for HIV or Hepatitis C. A federal regulation, OSHA's Blood Borne Pathogens Standard, is designed to minimize the risk of exposure to these diseases. Perhaps its most important requirement is what's known as "Universal Precautions." These precautions are designed to prevent transmission of blood borne pathogens. It means treating all human blood and other potentially infectious body fluids as if they are definitely infected with blood borne pathogens. Though the risk of infection is small, universal precautions help protect you from even that minimal chance.

**Universal Precautions** - Use Universal Precautions with Body Fluids that Could Contain Blood Borne Pathogens, such as:

1. Blood (Wet or Dry)
2. Semen or Vaginal Secretions
3. Any body fluid visibly containing blood (such as saliva from bleeding gums)
4. Any body fluid you can't distinguish from other body fluids

Additional body fluids (generally inside the body) that apply are: Cerebrospinal, Pleural, Peritoneal, Pericardial and Amniotic fluid. For example, Pleural fluid is found in the lining of the lungs.

Universal Precautions do not apply to the following unless they contain visible blood:
• Feces
• Nasal Secretions
• Sputum
• Sweat
• Tears
• Urine
• Vomit
• Saliva

These substances do not carry the threat of blood borne pathogens unless they contain blood, however, some of them do contain microorganisms that can cause other types of infection. Always Follow Universal Precautions in Jobs and Tasks with a Risk of Exposure. These may include: Transporting or handling blood and any contaminated or possibly contaminated materials including sharp objects, trash, laundry, etc. Cleaning areas that are or could be contaminated include working in an area or at a task where it’s unclear if there’s a risk of exposure to blood borne pathogens.

**Contact with non-intact skin or body tissue. What does it mean to “Use” Universal Precautions?**

It is a prevention strategy in which all blood and potentially infectious materials are treated as if they are infectious, regardless of the perceived status of the source. In other words, whether or not you think the blood/body fluid is infected with blood borne pathogens, you treat it as if it is. This approach is used in all situations where exposure to
blood or potentially infectious materials is possible. This means that you should follow the guidelines in situations where exposure may occur. Probably the first thing to do in any situation where you may be exposed to a blood borne pathogen is to ensure you are wearing the appropriate personal protective equipment (PPE). For example, you may have noticed that emergency medical personnel, doctors, nurses, dentists, dental assistants, and other health care professionals wear protective gloves. This is a simple precaution they take in order to prevent blood or potentially infectious body fluids from coming in contact with their skin. To protect yourself, it is essential to have a barrier between you and the potentially infectious material.

Examples of Using Personal Protective Equipment (PPE) as a Barrier against Infection. Include:

- Wearing gloves when you touch or handle potentially contaminated items or surfaces.
- Bandaging your cuts or broken skin.

Additional examples most often seen in a hospital setting are:

- Using masks and eye or face protection with solid side shields to protect mouth, eyes, nose, and face from splashes, sprays, or spatters.
- Wearing gowns, aprons, lab coats, and surgical caps when necessary to protect your body from splashes, sprays, and spatters.
- Using shoe covers or boots if there's a risk of exposure to large amounts of blood or body fluids or possibly contaminated broken glass.
Wear disposable gloves only once and replace them immediately if they're torn or contaminated. Remove all PPE when it's contaminated and before you go into a clean area or touch clean items. Remove contaminated PPE so it doesn't touch your skin.

Other important measures to reduce or prevent exposure to blood borne pathogens are:

Practicing Good Hygiene and Eliminating Possible Situations for Exposure.

Examples of these include:

- Hand washing – this is one of the most important practices used to prevent the spread of infection!
- Wash with soap and water as soon as possible after removing PPE, contacting potentially infectious materials, or completing a Consumer procedure
- Flush eyes, nose, and mouth with water after body fluid contact
- Don't eat, drink, smoke, apply cosmetics or lip balm, or handle contact lenses where there's a risk of blood borne pathogens exposure
- Don't store food or drink in such areas
- Keep the workplace clean

Understanding Your Risk: The principal risk to the healthcare provider is in relation to a skin penetrating injury with a sharp object (such as a needle, lancet or broken glass) that has been previously contaminated with infected blood or other qualifying body fluid/material. Another is the splashing of infected fluid onto broken skin (such as a cut on your hand) or the splashing onto mucosa (such as the inside of your mouth, nose or in the eyes). These situations do not mean infection will definitely occur. They only identify the scenarios of greatest risk were infection might occur. It's impossible to know if someone is infected with a blood borne pathogen just by looking at them, so it's
important to treat all the body fluids that can carry blood borne pathogens as if they are infected.

What to do if you are exposed? If you are stuck by a used needle or other sharp object or get blood or other potentially infectious fluid in your eyes, nose, mouth or on broken skin:

1. Immediately flood the exposed area with water and clean any wound with soap and water or a skin disinfectant if available.

2. Then report the incident to your employer.

**Points to Remember:**

- Universal Precautions provide protection against Blood Borne Pathogens.
- To protect yourself, it is essential to have a barrier between you and the potentially infectious material.
- A vaccine is available for Hepatitis B.
- Hand washing is one of the most important means of controlling the spread of infection.

The participants seemed to grasp the importance and procedures of the universal precautions.

The social worker began talking about the social stigmas of certain diseases such as HIV. She talked about how lonely patients with this disease can become because of people believing they brought their disease on themselves. She talked about her contact with patients with HIV that have been cut off by their families and also been shunned by faith communities. The chaplain talked about HIV patients afraid of death because of
their fear of God’s rejection. The hospice staff in agreement, stated patients with stigmas like HIV need volunteers to help with their spiritual journey.

4A. The following Sunday before-service the participants met with the researcher in our usual manner to discuss the previous session. Immediately one participant shared she lost a relative to AIDS and it was divisive to the family. She shared how the person’s parents divided and siblings were divided and it has not been a complete reconciliation years later. Another participant talked about how a family member suffering with cirrhosis of the liver has caused some embarrassment to his immediate family. A participant stated “It could be anyone of us that contracts any disease.” The researcher asked how this session had affected their concept of mission to hospice patients and their families. The participants unanimously agreed they saw a strong need for their church (participants) to get involved in the care of those who are dying and have loved ones dying. The participants expressed they feel more comfortable walking in a patients room after learning about universal precautions.

Our dialogue turned to the need for a ministry to hospice patients. Each participant talked about the aspects of hospice they didn’t know in the beginning of the program and what they know now. One participant asked the question - what is the most important thing we could say to a patient that is dying? The researcher shared with her the importance of listening and being present can be more valuable than talking. Another member spoke up and said, “I agree with that because when I lost my father there were people telling me about how I should feel. All I really wanted was to tell someone how I really felt.” The researcher informed the participants that they had only one more session left with the hospice staff. He encouraged them to reflect on the process of meeting with
the hospice staff and asked if they believed they could participate in a cohesively defined partnership with hospice? The entire group said yes. The researcher asked the group if the process helped them identify any fears of dying, and if so, has it helped them with those fears? Each participant gave the researcher an answer. Of the six participants, one said it helped prepare them to accept death and understand the dying process better. One said it helped with their view of dying which scared her. Another said the continued conversation about death helped him begin to overcome his fear. One said his awareness of death has expanded and his understanding has grown and this eases his anxiety about dying. One stated it helped them see it is about living as best as you can before you die and not about fixating on the fear of dying. The sixth participant said it helped her become aware of the different aspects of dying and how some experiences are common.

5. Pastor, chaplain, volunteer coordinator and participants to discuss “Church Mission to the Dying: The opportunity and need for volunteers.” The goal was to help the participants see the need for the church to reach out to hospice patients and their families.

The session took place on a Thursday evening at the church. The chaplain started the session with a story about his encounter with a dying patient who lived his 61 years of life separated from church. After he received a diagnosis of terminal head and neck cancer, a chaplain from the hospital came in his room and led him to Christ. When the patient came on Heartland Hospice service they talked about his being baptized in his home. The Sunday the chaplain baptized him Mt. Carmel Christian Methodist Episcopal Church prayed over the water and the first Bible he would ever own. This man died less than two weeks after his baptism and his caregiver said he died with a confidence he would see his mother in death because they both were baptized. This patient had no
experience with church and did not know how, nor was he able to seek a church out. The chaplain emphasized the importance of the church mission to seek out and offer ministry to the hospice patients and their family."

The volunteer coordinator talked about the importance of hospice patients and families to have volunteers come and help them. She talked about how important help with activities of daily living is to a hospice family; help around the house, sitting with a patient for socialization and other tasks. The volunteer told the participants it can be very meaningful for the volunteer also. The volunteer outlined the training which would cover infection control, cultural and religious sensitivity, right of privacy, proper documentation, liability, along with a mandatory background check. The participants wanted to know if there were standard time limits for volunteering. The Volunteer coordinator assured them they could volunteer as much or as little as they wanted. She handed out volunteer applications (see appendix I). Each participant accepted an application and thanked the volunteer coordinator.

5A. On Sunday morning before service the participants and the researcher had their last project meeting. The participants stated they were surprised that volunteer work was so important to hospice patients and their families. One member stated she thought people would want to be alone during the dying process. However, it made sense to her having help around the house would be a lift in spirit. The group’s dialogue naturally went to how the church can be more responsive to hospice patients. The participants agreed to volunteer for hospice would be a great outreach for Mount Carmel CME Church. Five of the participants were willing to volunteer, one participant stated she would be willing but she doesn’t have transportation. The participants thanked the
researcher for the exposure to hospice. One participant inquired about the possibility of her mother qualifying for hospice, and another member referred a church member for hospice. The researcher later facilitated both going on Heartland Hospice service. He handed out the final questioner (see appendix I) and thanked the participants as the researcher, and assured them as their pastor, they would continue to probe the issues of hospice, death and dying.
CHAPTER 6

Evaluation and Reflection

Ministry Issue Addressed

The purpose of this project was to train volunteers working in a church to become hospice volunteers. A total of eight members of Mount Carmel Methodist Episcopal Church comprised the group. The hospice education was administered by employees from a nearby hospice center.

In the researcher’s context of a hospice chaplain, he was exposed to hospice patients and their families experiencing end-of-life journeys without the comfort and support of a faith community. Some of these patients and family members had been separated from a faith community for an extended amount of time; although they desired additional support they had no point of reference for connecting with a faith community. Other patients and families in need of a faith community were so consumed with the dying process they did not have time to find a faith community. While the chaplain’s position is pivotal in hospice care, their case loads are frequently heavy—limiting time allotted for in-depth ministry to each patient. It is the researcher’s contention, that even when a hospice chaplain offers the best care possible, visitation by a personal faith community of two or more visits enhances the spiritual care of the dying person. Therefore, to develop teams of church members as hospice volunteers to work alongside the hospice team will be significant to the plan of care for the dying patient. Along with the patient, the family will also benefit from the presence of the faith community working in conjunction with the health care professionals. In the meantime, the faith community would fulfill a missionary mandate.
Ministry Challenge

There were numerous “ministry” challenges encountered. For instance, Mount Carmel Christian Methodist Episcopal Church was the setting for hospice volunteer meetings: no member has ever volunteered to serve with hospice patients in the history of this church. Once members volunteered, there were several other challenges identified in training them to serve as hospice volunteers. After several meetings with a number of church members, the researcher identified three possible reasons why hospice volunteering was absent in the history of the church:

1. Deeply imbedded myths about hospice were noted among the church members. None of the members had a clear understanding of hospice. Although there were members who had direct experience with hospice centers and patients under hospice care, their understanding of the hospice philosophy was unclear to the novice. The myths about hospice were numerous. In particular, hospice care speeds up a person’s death and hospice isn’t for people of faith—these two myths were repeatedly voiced.

2. Unprocessed fear of death was another reason members avoided volunteering. In Bible study settings and personal conversations it became apparent that a large percent of the congregation was uncomfortable discussing issues surrounding death and dying or end of life issues. Some members believed talking about death would cause the sick to die faster. Although members listened to sermons and discussed heaven or the after-life, none of them had much experience with the end of life process.

3. Members avoided volunteering with hospice because failure to grasp the importance of the position of volunteer. In a dialog about hospice patients and families’ end of life journey, members verbalized their surprise about the psychosocial
needs/issues involved with caring for the dying. Therefore, the researcher set out to dispel their myths about hospice by securing assistance for them to process and alleviate their fear of death, and assisting them at seeing the need to participate in caring for hospice patients, hoping they would pursue becoming hospice volunteers.

Project Design

The project was designed to assist the participants with the ministry challenges described above. The goals of the project were to educate and offer tools to assist participants to become willing to be hospice volunteers. The timeframe for each session was scheduled for one hour. Each session was conducted by a professional person with experience in hospice care. The format for the education sessions were five sessions in an open forum to educate and offer tools that would guide participants to a willingness to become hospice volunteers. The sessions were on a framework of no less than sixty-minutes in length and included handouts for the participants. The goal of session one was to introduce participants to the concept of hospice care and dispel any myths about hospice and hospice care. Session two was centered on helping participants become familiar with techniques of therapeutic communication about death and dying. Thirdly, to assist in alleviating their fears of their own mortality, each participant was required to discuss their own mortality through reflecting and preparing for their own end of life journey.

Session Three was a continuation of session II which included a discussion on the fears of death and dying and developing deeper understanding of psychosocial process of living until death.
Session four was designed to assist participants to achieve a level of comfort when offering care to patients with communicable and stereotyped diseases such as AIDS. The goal of session five was to assist participants with verbalizing their understanding and appreciation of the need for participating in a volunteer program such as this one.

**Method of Evaluating the Project**

The researcher used qualitative data analysis to evaluate the project. Following each session with the hospice professionals the researcher held a feedback session with the participants. In this meeting, the participants discussed their understanding of the content of each session and how this information affected each of them personally. Data were also generated by this researcher through observation and listening to the participants during this less formal session with the hospice staff where feedback was given to participants. This method of data collection was invaluable for the researcher to gage how the participants were responding to the information provided in the sessions. In addition, insight was acquired about their reflection on the subject matter in the feedback meetings.

The participants were also given questionnaires to complete after the first and last session with the hospice staff. The questionnaires were revealing regarding the progress of each participant. The blend of observation, dialog, questionnaires, and actions taken by the participants regarding family members becoming hospice patients, provided the researcher with a definite picture of the effectiveness of the project.
Project Evaluation

Session one began with a strong icebreaker that involved each participant. The participants expressed their apprehension about their initial feelings of coming into the project. There was a fear of being overwhelmed by the gruesomeness of their concept of hospice, death and dying. Meeting with the hospice staff face to face verses reading about hospice in the words of the participants put a face on hospice. In the feedback sessions the members expressed “surprise” about how many of their myths were dispelled about hospice. Each of the participants revealed they had never talked about death and dying in a forum before. They felt “pleased” that they had overcome fear of being overwhelmed by what they called “Doom and gloom.” There remained a prevailing fear among a few participants that talking about death might bring it in their lives prematurely. However, all of the participants expressed excitement about what the project had in store for the future of hospice and the church.

In Session two the Medical Director of Heartland Hospice spoke about end of life issues. This discussion stood out as a “one of a kind” experience for the participants. The doctor helped them to understand the need to have an open discussion about death and dying. According to several participants, “they went home and pondered how they would want to live out their last days?” Further, they were very engaging with the doctor regarding South Carolina Health Care Power of Attorney. Their questions were in the area of “would that mean once the form was signed it was final?” The physician assured them at any time a patient, if able to communicate, could resend the order. After this session, the participants made a point to personally thank the doctor for sharing this important information… Many of their fears were eliminated.
In the feedback session the participants were eager to share how they had taken steps to thinking about their own end of life desires. Three of the six shared that they sat down with their spouse and filled out the South Carolina Health Care Power of Attorney Form. The consensus of the group consisted of a more relaxed feeling about talking about death inclusive of their own, after having a frank conversation about hospice, death and dying with the physician. One member described it as liberating to not have the fear stifling the conversation around death. Because of their increased “Level of comfort” one person referred a church member to be evaluated for hospice. This would be one of eight such referrals during the course of the project.

Session three according to participants, assisted them to “go deep” into their personal fears of death and dying. They all expressed surprised at the openness of the patients regarding death. During this session, one member began to cry and all of the other participants came to her rescue. When asked the reason for the tears, the participant revealed her own end of life journey was at the core of her sadness. Each participant then shared how Session III heightened their awareness of their own fears, concerns and faith about death and dying. The participants also expressed gratitude to the hospice staff for the material they received and for encouraging them to have an open session about their thoughts of death and dying.

The energy level during this feedback session was very high. All of the participants reported how reflecting on their own mortality brought about various feelings such as the fear of dying. The participants verified after this session they could not help but admit the fear of the unknown was troubling to them. The group also agreed the session had a unique effect on them causing each to consider their feelings about death
and dying. Some participants came face to face with their anger over the death of loved ones. The session also gave the participants an understanding of the stages of grief which helped them process their feelings. Their faith was also a valuable tool in addressing their deep thoughts of death and dying, said two participants.

Outside of the session, at separate times, participants approached the researcher about possible hospice admissions for their parents. Working together as a team, we were able to successfully get each of their relatives admitted into hospice care. Both attributed the project for giving them the insight and confidence their family would benefit from hospice service. The participants began to rally around the hospice patients in the church and their families. They were excited about utilizing the information they learned and experienced from the project.

Session four focused on stereotypes and myths they previously held regarding HIV. The participants admitted their fears about offering care to patients with communicable diseases. The participants stated they were comfortable disclosing their discomfort in certain situations with patients that contracted HIV. The session empowered them to have a sense of protection and safety. In addition, the participants had a clearer understanding of how some diseases are transmitted.

In the feedback sessions, one member admitted she had a relative that died of complications from AIDS. She shared with the group that her family was split because of differing views about the disease. This participant’s family would have benefited from a dialog similar to the one in session four. The participants were also eager to share their experiences by offering care to the Mt. Carmel families on hospice. At this point in the project, three of the participants had relatives receiving hospice care.
The common theme was the effort it takes for a family to participate in a loved one’s care. The group set schedules of how they would relieve families (Church members on hospice) by sitting with the patient. There were times when participants would organize food to be prepared and delivered to homes. The participants had mixed emotions, sad because people in the congregation were sick and at the end of life, yet glad that the project prepared them to understand what was taking place.

The participants were acquiring direct knowledge about hospice through the care of family member or being present with other church members on hospice service. Towards the end of the project five of the participants had family members in hospice. This gave them an opportunity to practice what they had learned through the project.

During session five many were tearful because some of the participants were undergoing hospice care. At this point, eight persons from the church had been admitted on hospice service and four died as a result of the various disease processes. The story about John that was told in this session reminded some of the group of their loved ones that were dead and others of their loved ones that were dying. The participants at this point in the project were well aware of the need to be hospice volunteers. The group had used the knowledge that they acquired from the project in their own lives and the lives of others. All church members who were trained were willing to become volunteers for hospice. They affirmed it would be a great ministry for the church to send volunteers to assist people in their end of life journeys.

The feedback for session five began with tears for the group as they looked back on their progression in the project. The group affirmed their lives would never be the same because of the project. Some started the project with a semi closed attitude but
finished with keen compassion for those in the dying process and their families. The participants reflected on the stages of their development and were clear their life was transformed by the project. The participants stated there were times during the project those fears of death and dying were very strong. However, the understanding and tools they learned from the project kept them from feeling overwhelmed. The participants, whose family members died during the course of the project, found the volunteer type support they received from the group members aided them in the grief process. Some participants reported back their loved ones thanked them before they died for being present. They reported they might not have been able to be present with the intensity they had, had it not been for their experience in the project.

The participants also completed a survey which revealed the following: (1) the group believed the continuity of the meetings with hospice personnel and the firsthand experience helped them to dispel the myths about hospice. (2) They expressed gratitude for being participants which helped them adequately address their unresolved fear of death. (3) The comments painted a picture, despite the pain of loss of their loved ones; they believed “God allowed the project to come their way to help them prepare for more effective ministry to hospice patients.”

**Project Limitations**

The limitations of the project were as follows; eight participants were an adequate representation of the church. However, if the entire church were to incorporate this project as a Christian education component in the church curriculum, it would have been able to have a much further reach. The researcher witnessed how the participants responded to hospice patients within their families of origin and church families, but did
not get to observe them with outside hospice patients. However, he is confident the participants will be very successful volunteers. Further research is needed in helping faith communities get involved with local hospices to share in care for the hospice patients and their families in the communities in which they live.

**Researcher’s Reflections**

It seems long ago and yet just yesterday when the need for a partnership between hospice and the church became a reality for the researcher. He remembers clearly, the feeling of sadness as a hospice chaplain, when this one particular man, whose wife was dying, had no faith community to help them with their end of life situation. The researcher helped him the best he could, with a listening ear, words of encouragement and spiritual support. He also helped with the funeral arrangement and burial. However, that case left a burning in his heart to find a way to bridge hospice and the church. Therefore, when the opportunity to enroll in the Doctor of Ministry program at the Interdenominational Theological Center became a reality, the researcher’s hope became a strong possibility.

Under the direction of the faculty, the researcher began to think about and prepare this project. It was important to start with the research in Mount Carmel on their historical relationship with hospice. There were no strong ties to hospice and very little understanding about what hospice care entailed. There had never been a hospice volunteer or a hospice staff member communicating in any form or fashion with the church. Through group and private conversation the researcher became aware of a hesitancy to discuss death and dying. He suspected this was due to unresolved fear on the subject matter. It was apparent these caring people were not aware of the need that was
happening all around them in the end of life journey of their neighbors, families and friends.

The project of leading a group of members in the church to become hospice volunteers had to address three areas: (1) myths about hospice (2) fear of death and dying and (3) seeing the need to volunteer. It was in consultation from the literature, dialog with hospice staff, and careful and prayerful reflection that the five sessions were designed and coordinated. Session by session, the researcher watched the growth of the participants. After session one entitled “What is hospice,” he observed “walls of misunderstanding” collapse. In their feedback session, he heard new language regarding hospice from the participants. This was a difference from his initial conversation with the church members. The responses to the questionnaire reflected a strong possibility they could be guided to becoming volunteers.

However, it was after session two when there was a demonstrative shift in the participants taking place. Following the session with the medical director, what the researcher calls a Divine phenomenon, occurred. The participants developed awareness and a comfort level with hospice and referred a church member to hospice service. As the sessions progressed the participants started organizing open discussions on their fears, worries, concerns and faith in God about death and dying. Through this observation and discussions with the participants it was clear to the researcher a change was taking place in the lives of these participants.

By the fourth session the Divine phenomenon had taken form. This is what the researcher calls the Divine phenomenon; through the course of the project eight members of Mount Carmel Church became hospice patients. Six of the hospice patients had family
ties with project participants, including the researcher. Of the eight patients admitted to hospice care, five died during the project. The researcher witnessed firsthand how the project participants utilized the information from the project in caring for their loved ones on hospice, their other family members and each other. (1) They held frank discussions with the patients about death and dying. (2) They were able to gage stages of death and dying, and (3) helped non-project participants to understand the five stages. The participants arranged to help by sitting with patients so primary caregivers could be relieved. After the deaths of the patients/church members, the researcher observed a difference in how the project participants offered care to the family verses non-project participants from the congregation. Non-participants were more likely to tell the bereaved how they should feel and behave “don’t cry you shouldn’t be sad you should be happy for her/him, she is in a better place.” The participants on the other hand, appeared to listen to the grieving persons and were comfortable in just being present. By session five the researcher had no doubt the group would make excellent hospice volunteers and in fact, were operating within the congregation as volunteers. Each participant by way of Divine phenomenon, had firsthand experience in being a family member with someone on hospice or offering (volunteer) help to a church member on hospice. The group definitely became aware of the need for the church to have hospice volunteers active. In the assessment of this researcher, the goals of dispelling myths of hospice, helping participants with unresolved fear of death and dying and realizing the need for hospice volunteers were achieved. These participants were committed to becoming hospice volunteers and they provided a ministry to hospice patients in the congregation.
In the mind of the researcher the quality of end of life care was increased for church members who became hospice patients as a direct result of the project. These patients had more people attending to them and their families, including church members at their bedsides who listened to “farewell discourses.” Hospice patients and their families shared with the researcher that the presence of project participants made a difference in the dying process.

Heartland Hospice staff developed a close bond with project participants through project sessions and caring for members of Mount Carmel as patients. Because of this bond, hospice staff reported to the researcher they have a broader picture of how collaboration between hospice and faith communities can better assist their patients. The staff had their myths shattered that the church could not be helpful. Some staff shared with the researcher the project assisted them with their fears of death and dying. Hospice patients and their families along with hospice staff have benefited greatly through this project.

This project was completed with great satisfaction. The researcher watched a group of caring people with misunderstandings and fears grow before his eyes. When the researcher started this process, it was to help persons receive and give the gift of caring to hospice patients and their families in the end-of-life journey. Without reservation it is safe to say it was the researcher who was helped the most in this project. Each session helped him to better cope with his mother’s dying process. After her death the same group he wanted to encourage at becoming hospice volunteers offered him unforgettable bereavement care.
During the course of this project the researcher had his own myth dispelled regarding how quickly church members would bond and offer end of life care with hospice. In the beginning of the project it was clear to the researcher participants had issues with hospice, death and dying, and believed there was a need for the local church to become involved in caring for hospice patients and their families. He assumed it would take all ten sessions before members would begin learning how to offer effective end of life care. This researcher was wrong; in four sessions the group was actively referring to hospice with a clear understanding of who might qualify and what services hospice offers.

This project helped the researcher identify his fears of death and dying lying dormant. Through reading project literature, observation and participation in project sessions, and reflection, the researcher’s feelings regarding death surfaced: loneliness, separation, pain, nothingness, and abandonment. These feelings were compounded by the experience of taking care of and watching his mother die. Through the course of the project the researcher wrestled with anticipatory grief of his own and his mother’s death. In no small manner the people and material associated with the project helped equip the researcher in this anticipatory grief as well as process the death of his mother.

As a hospice chaplain, the researcher became aware of the need of faith-based hospice volunteers caring for patients and their families. However, it was not until the researcher’s mother became a hospice patient living with him and his wife that he understood the immense need for hospice volunteers. Being primary caregivers was a daunting task for the couple. The researcher’s mother barely slept many nights because her pain was so great; this meant the entire household was up all night. It was very
emotionally and physically taxing being unable to fix the situation, knowing Mrs. Joan Wilks was dying. The researcher became aware hospice volunteers may not be available to rescue or alter the impending death but their presence at key moments could offer great relief for those whom they serve. At the start of this project the researcher was aware of the need for hospice volunteers from the church. However, through experience of his mother’s death and dying he found out firsthand the need to have the comfort of a faith community walking with one in an end of life journey.

**Future Implications for Ministry**

The researcher suspects there are many local congregations without hospice volunteers. The researcher would further speculate the reason for this is due to: myths about hospice, unprocessed fear of death and dying, and failure to see the need to offer a volunteer ministry to hospice patients. It is the researcher’s belief that many congregations could follow the project steps and experience a transformation similar to Mount Carmel. With proper coordination between a hospice liaison, church representative, and willing participants, this project could potentially add great value to the life and ministry of many churches.

There are people in congregations that would benefit from hospice services but they are blocked by misunderstandings, fears, and unintentional blindness. There are also members in the congregation who would be excellent in journeying with hospice patients and their families and become hospice volunteers as a result of duplicating this project. This project has the potential to enable conversations about end of life journeys that can affect health care for years to come.
The healthcare industry is at times in a bottleneck on how to use resources in end-of-life care. This often happens when there is no living will or families are not clear on an incapacitated patient’s medical care wishes. However, when the church takes a participating role in the end of life awareness and care the results will be very impactful.

**Conclusion**

As a result of this project the end-of-life care for a number of people was enhanced through a joint plan of care effort between Heartland hospice and Mount Carmel Christian Methodist Episcopal Church. The families remain grateful for the support provided. Project participants have all agreed to become hospice volunteers as they have real-life experience with caring for hospice patients and their families. Each participant has dispelled myths about hospice and they have developed tools to cope with the fears associated with death and dying. Because of the number of hospice patients within their congregation, participants are acutely aware of the missionary call to become hospice volunteers.

The experience of facilitating this project has been both wonderful and painful for the researcher. The researcher is deeply grateful for all this project has entailed. As a result of this project the researcher found a measure of healing and comfort in the loss of his mother. Therefore he is grateful to everyone associated directly or indirectly with this effort. God is and God will be the God of complete and infinite comfort.
Appendix A

Questionnaire for Doctor of Ministry Project
Interdenominational Theological Center
Administered by D. Min. Student: Keith Wilks

Directions: Circle the letter of the phrase that best describes you.

At the beginning of this project . . .

A. I have had experience with hospice.
B. I have no experience with hospice.
   If you have had experience, describe your experience with hospice:

Participation in this project has . . .

A. not helped my understanding of hospice.
B. affirmed my understanding of hospice.
C. helped me to change my opinion of hospice.

Discussions in this project have affected my view of death and dying . . .

A. very little.
B. somewhat.
C. strongly.

Explain:

D. Min. Project Questionnaire Administered by Keith Wilks
As a result of my participation in this project I am . . .

A. not likely to participate in a volunteer ministry to hospice patients.
B. likely to participate in a volunteer ministry to hospice patients.
C. in need of more information before I would participate in a ministry to hospice patients.

Explain

Would I recommend hospice to someone . . .

A. Yes
B. No

Explain

Comments

D. Min. Project Questionnaire Administered by Keith Wilks
Hospice Myths

1) MYTH: Hospice patients cannot go to the hospital
TRUTH: Hospice is a philosophy of care that focuses on quality of life.

2) MYTH: To get hospice care, a patient must have a 24-hour caregiver
TRUTH: Hospice is a philosophy of care that focuses on quality of life.

3) MYTH: Hospice is a place
TRUTH: Hospice in a philosophy of care that focuses on quality of life.

4) MYTH: Hospice cares only for cancer patients
TRUTH: Hospice cares for all eligible patients regardless of the diagnosis.

5) MYTH: Hospice care can be delivered only in a patient's home
TRUTH: Hospice care can be delivered anywhere a patient calls home including skilled nursing, assisted living, and retirement facilities.

Hospice Myths (cont.)

6) MYTH: The patient and family must be ready to accept impending death to have hospice care
TRUTH: The patient must be eligible and have a full understanding of hospice and the palliative (comfort), not curative (well-care) nature of the treatment provided. The role of hospice can be to prepare the patient and family but the patient does not have to be ready to die prior to receiving hospice.

7) MYTH: To get hospice care, a patient must first stop receiving treatment
TRUTH: The Medicare Hospice Benefit does not mandate that the patient stop treatments necessary to provide comfort.

8) MYTH: A patient must have a DNR to be eligible for hospice
TRUTH: The regulation actually mandates that hospices not discriminate against patients because of any advance directive choices they have or have not made.
Hospice Myths (continued)

9) MYTH: A physician's order is required to visit with a patient to discuss services

TRUTH: Patients can choose for us to meet with them and discuss the benefit of hospice. We cannot provide care to a patient without a physician's order. We will work with the patient's physician to determine the individual's medical care needs.

10) MYTH: The patient's doctor will not get paid if the patient is on the Medicare Hospice Benefit

TRUTH: The patient's physician may continue to bill for services as appropriate.
Summary

- Advance care planning is a fundamental palliative care skill
- Advance care planning reduces family burden at end-of-life
- The identification of the proxy is an important goal
- The discussion is more important than the documents
Topics to consider

- Pain management
- Artificial nutrition and hydration
- CPR
- Mechanical ventilation
- Blood transfusion
- Dialysis
- Antibiotics, HAART, other meds
Elicit patient values and goals

- Use values questions:
  - "What makes your life worth living?"
  - "How would you like to spend your last days?"
  - "What are your spiritual beliefs that might affect treatment choices?"
Identify a proxy decision-maker

- Entrusted to speak for the patient
- Involved in all the discussions
- Must be willing, able to take the proxy role
Educate patient and proxy

- Define key medical terms
- Explain benefits, burdens of treatments:
  - Life-support may only be short-term
  - Any intervention can be refused
  - Recovery cannot always be predicted
Appendix D

Health Care Power of Attorney, South Carolina

HEALTH CARE POWER OF ATTORNEY

A health care power of attorney executed on or after January 1, 2007 must be substantially in the following form (S. C. Code Section 62-5-504 (D)):

INFORMATION ABOUT THIS DOCUMENT

THIS IS AN IMPORTANT LEGAL DOCUMENT. BEFORE SIGNING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:

1. THIS DOCUMENT GIVES THE PERSON YOU NAME AS YOUR AGENT THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU IF YOU CANNOT MAKE THE DECISION FOR YOURSELF. THIS POWER INCLUDES THE POWER TO MAKE DECISIONS ABOUT LIFE-SUSTAINING TREATMENT. UNLESS YOU STATE OTHERWISE, YOUR AGENT WILL HAVE THE SAME AUTHORITY TO MAKE DECISIONS ABOUT YOUR HEALTH CARE AS YOU WOULD HAVE.

2. THIS POWER IS SUBJECT TO ANY LIMITATIONS OR STATEMENTS OF YOUR DESIRES THAT YOU INCLUDE IN THIS DOCUMENT. YOU MAY STATE IN THIS DOCUMENT ANY TREATMENT YOU DO NOT DESIRE OR TREATMENT YOU WANT TO BE SURE YOU RECEIVE. YOUR AGENT WILL BE OBLIGATED TO FOLLOW YOUR INSTRUCTIONS WHEN MAKING DECISIONS ON YOUR BEHALF. YOU MAY ATTACH ADDITIONAL PAGES IF YOU NEED MORE SPACE TO COMPLETE THE STATEMENT.

3. AFTER YOU HAVE SIGNED THIS DOCUMENT, YOU HAVE THE RIGHT TO MAKE HEALTH CARE DECISIONS FOR YOURSELF IF YOU ARE MENTALLY COMPETENT TO DO SO. AFTER YOU HAVE SIGNED THIS DOCUMENT, NO TREATMENT MAY BE GIVEN TO YOU OR STOPPED OVER YOUR OBJECTION IF YOU ARE MENTALLY COMPETENT TO MAKE THAT DECISION.

4. YOU HAVE THE RIGHT TO REVOKE THIS DOCUMENT, AND TERMINATE YOUR AGENT'S AUTHORITY, BY INFORMING EITHER YOUR AGENT OR YOUR HEALTH CARE PROVIDER ORALLY OR IN WRITING.

5. IF THERE IS ANYTHING IN THIS DOCUMENT THAT YOU DO NOT UNDERSTAND, YOU SHOULD ASK A SOCIAL WORKER, LAWYER, OR OTHER PERSON TO EXPLAIN IT TO YOU.

6. THIS POWER OF ATTORNEY WILL NOT BE VALID UNLESS TWO PERSONS SIGN AS WITNESSES. EACH OF THESE PERSONS MUST EITHER WITNESS YOUR SIGNING OF THE POWER OF ATTORNEY OR WITNESS YOUR ACKNOWLEDGMENT THAT THE SIGNATURE ON THE POWER OF ATTORNEY IS YOURS.

THE FOLLOWING PERSONS MAY NOT ACT AS WITNESSES:
A. YOUR SPOUSE, YOUR CHILDREN, GRANDCHILDREN, AND OTHER LINEAL DESCENDANTS; YOUR PARENTS, GRANDPARENTS, AND OTHER LINEAL ANCESTORS; YOUR SIBLINGS AND THEIR LINEAL DESCENDANTS; OR A SPOUSE OF ANY OF THESE PERSONS.

B. A PERSON WHO IS DIRECTLY FINANCIALLY RESPONSIBLE FOR YOUR MEDICAL CARE.

C. A PERSON WHO IS NAMED IN YOUR WILL, OR, IF YOU HAVE NO WILL, WHO WOULD INHERIT YOUR PROPERTY BY INTESTATE SUCCESSION.

D. A BENEFICIARY OF A LIFE INSURANCE POLICY ON YOUR LIFE.

E. THE PERSONS NAMED IN THE HEALTH CARE POWER OF ATTORNEY AS YOUR AGENT OR SUCCESSOR AGENT.

F. YOUR PHYSICIAN OR AN EMPLOYEE OF YOUR PHYSICIAN.

G. ANY PERSON WHO WOULD HAVE A CLAIM AGAINST ANY PORTION OF YOUR ESTATE (PERSONS TO WHOM YOU OWE MONEY).

IF YOU ARE A PATIENT IN A HEALTH FACILITY, NO MORE THAN ONE WITNESS MAY BE AN EMPLOYEE OF THAT FACILITY.

7. YOUR AGENT MUST BE A PERSON WHO IS 18 YEARS OLD OR OLDER AND OF SOUND MIND. IT MAY NOT BE YOUR DOCTOR OR ANY OTHER HEALTH CARE PROVIDER THAT IS NOW PROVIDING YOU WITH TREATMENT; OR AN EMPLOYEE OF YOUR DOCTOR OR PROVIDER; OR A SPOUSE OF THE DOCTOR, PROVIDER, OR EMPLOYEE; UNLESS THE PERSON IS A RELATIVE OF YOURS.

8. YOU SHOULD INFORM THE PERSON THAT YOU WANT HIM OR HER TO BE YOUR HEALTH CARE AGENT. YOU SHOULD DISCUSS THIS DOCUMENT WITH YOUR AGENT AND YOUR PHYSICIAN AND GIVE EACH A SIGNED COPY. IF YOU ARE IN A HEALTH CARE FACILITY OR A NURSING CARE FACILITY, A COPY OF THIS DOCUMENT SHOULD BE INCLUDED IN YOUR MEDICAL RECORD.

HEALTH CARE POWER OF ATTORNEY

(S.C. STATUTORY FORM)

1. DESIGNATION OF HEALTH CARE AGENT

1. __________, hereby appoint:

(Principal)
Agents:

(Name)

Address:

Telephone: home: ______ work: ______ mobile: ______

As my agent to make healthcare decisions for me as authorized in this document.

Successor Agent: If an agent named by me dies, becomes legally disabled, resigns, refuses to act, becomes unavailable, or if an agent who is my spouse is divorced or separated from me, I name the following as successors to my agent, each to act alone and successively, in the order named:

a. First Alternate Agent:

Address:________________________________________

Telephone: home: ______ work: ______ mobile: ______

b. Second Alternate Agent:

Address:________________________________________

Telephone: home: ______ work: ______ mobile: ______

Unavailability of Agent(s): If at any relevant time the agent or successor agents named here are unable or unwilling to make decisions concerning my healthcare, and those decisions are to be made by a guardian, by the Probate Court, or by a surrogate pursuant to the Adult Healthcare Consent Act, it is my intention that the guardian, Probate Court, or surrogate make those decisions in accordance with my directions as stated in this document.

2. EFFECTIVE DATE AND DURABILITY

By this document I intend to create a durable power of attorney effective upon, and only during, any period of mental incompetence, except as provided in Paragraph 3 below.

3. HIPAA AUTHORIZATION

When considering or making healthcare decisions for me, all individually identifiable health information and medical records shall be released without restriction to my healthcare agent(s) and/or my alternate healthcare agent(s) named above including, but not limited to, (i) diagnosis, treatment, other healthcare, and related insurance and financial records and information associated with any past, present, or future physical or mental health condition including, but not limited to, diagnosis or treatment of HIV/AIDS, sexually transmitted disease(s), mental illness, and/or drug or alcohol abuse and (ii) any written opinion relating to my health that such healthcare agent(s) and/or alternate healthcare agent(s) may have requested. Without limiting the generality of the foregoing, this release authority applies to all health information and medical
records governed by the Health Information Portability and Accountability Act of 1996 (HIPAA). 42 USC 1320d and 45 CFR 160-164; is effective whether or not I am mentally competent; has no expiration date; and shall terminate only in the event that I revoke the authority in writing and deliver it to my health care provider.

4. AGENT’S POWERS

I grant to my agent full authority to make decisions for me regarding my health care. In exercising this authority, my agent shall follow my desires as stated in this document or otherwise expressed by me or known to my agent. In making any decision, my agent shall attempt to discuss the proposed decision with me to determine my desires if I am able to communicate in any way. If my agent cannot determine the choice I would want made, then my agent shall make a choice for me based upon what my agent believes to be in my best interests. My agent’s authority to interpret my desires is intended to be as broad as possible, except for any limitations I may state below.

Accordingly, unless specifically limited by the provisions specified below, my agent is authorized as follows:

A. To consent, refuse, or withdraw consent to any and all types of medical care, treatment, surgical procedures, diagnostic procedures, medication, and the use of mechanical or other procedures that affect any bodily function, including, but not limited to, artificial respiration, nutritional support and hydration, and cardiopulmonary resuscitation;

B. To authorize, or refuse to authorize, any medication or procedure intended to relieve pain, even though such use may lead to physical damage, addiction, or hasten the moment of, but not intentionally cause, my death;

C. To authorize my admission to or discharge, even against medical advice, from any hospital, nursing care facility, or similar facility or service;

D. To take any other action necessary to making, documenting, and assuring implementation of decisions concerning my health care, including, but not limited to, granting any waiver, or release from liability required by any hospital, physician, nursing care provider, or other health care provider; signing any documents relating to refusal of treatment or the leaving of a facility against medical advice, and pursuing any legal action in my name, and at the expense of my estate to force compliance with my wishes as determined by my agent, or to seek actual or punitive damages for the failure to comply.

E. The powers granted above do not include the following powers or are subject to the following rules or limitations:
5. ORGAN DONATION (INITIAL ONLY ONE)

My agent may ___; may not ___ consent to the donation of all or any of my tissue or organs for purposes of transplantation.

6. EFFECT ON DECLARATION OF A DESIRE FOR A NATURAL DEATH (LIVING WILL)

I understand that if I have a valid Declaration of a Desire for a Natural Death, the instructions contained in the Declaration will be given effect in any situation to which they are applicable. My agent will have authority to make decisions concerning my health care only in situations to which the Declaration does not apply.

7. STATEMENT OF DESIRES CONCERNING LIFE-SUSTAINING TREATMENT

With respect to any Life-Sustaining Treatment, I direct the following:

(INITIAL ONLY ONE OF THE FOLLOWING 3 PARAGRAPHS)

(1) ___ GRANT OF DISCRETION TO AGENT. I do not want my life to be prolonged nor do I want life-sustaining treatment to be provided or continued if my agent believes the burdens of the treatment outweigh the expected benefits. I want my agent to consider the relief of suffering, my personal beliefs, the expense involved and the quality as well as the possible extension of my life in making decisions concerning life-sustaining treatment.

OR

(2) ___ DIRECTIVE TO WITHHOLD OR WITHDRAW TREATMENT. I do not want my life to be prolonged and I do not want life-sustaining treatment:

a. if I have a condition that is incurable or irreversible and, without the administration of life-sustaining procedures, expected to result in death within a relatively short period of time; or

b. if I am in a state of permanent unconsciousness.

OR

(3) ___ DIRECTIVE FOR MAXIMUM TREATMENT. I want my life to be prolonged to the greatest extent possible, within the standards of accepted medical practice, without regard to my condition, the chances I have for recovery, or the cost of the procedures.

8. STATEMENT OF DESIRES REGARDING TUBE FEEDING
With respect to Nutrition and Hydration provided by means of a nasogastric tube or tube into the stomach, intestines, or veins, I wish to make clear that in situations where life-sustaining treatment is being withheld or withdrawn pursuant to Item 7. (INITIAL ONLY ONE OF THE FOLLOWING THREE PARAGRAPHS):

(a) ____ GRANT OF DISCRETION TO AGENT. I do not want my life to be prolonged by tube feeding if my agent believes the burdens of tube feeding outweigh the expected benefits. I want my agent to consider the relief of suffering, my personal beliefs, the expense involved, and the quality as well as the possible extension of my life in making this decision.

OR

(b) ____ DIRECTIVE TO WITHHOLD OR WITHDRAW TUBE FEEDING. I do not want my life prolonged by tube feeding.

OR

(c) ____ DIRECTIVE FOR PROVISION OF TUBE FEEDING. I want tube feeding to be provided within the standards of accepted medical practice, without regard to my condition, the chances I have for recovery, or the cost of the procedure, and without regard to whether other forms of life-sustaining treatment are being withheld or withdrawn.

IF YOU DO NOT INITIAL ANY OF THE STATEMENTS IN ITEM 8, YOUR AGENT WILL NOT HAVE AUTHORITY TO DIRECT THAT NUTRITION AND HYDRATION NECESSARY FOR COMFORT CARE OR ALLEVIATION OF PAIN BE WITHDRAWN.

9. ADMINISTRATIVE PROVISIONS

A. I revoke any prior Health Care Power of Attorney and any provisions relating to health care of any other prior power of attorney.

B. This power of attorney is intended to be valid in any jurisdiction in which it is presented.

BY SIGNING HERE I INDICATE THAT I UNDERSTAND THE CONTENTS OF THIS DOCUMENT AND THE EFFECT OF THIS GRANT OF POWERS TO MY AGENT.

I sign my name to this Health Care Power of Attorney on

this ___ day of ___, 20___. My current home address is:

__________________________________________________________

Principal's Signature:_______________________________________

Print Name of Principal:______________________________________
I declare, on the basis of information and belief, that the person who signed or acknowledged this document (the principal) is personally known to me, that he/she signed or acknowledged this Health Care Power of Attorney in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence. I am not related to the principal by blood, marriage, or adoption, either as a spouse, a lineal ancestor, descendant of the parents of the principal, or spouse of any of them. I am not directly financially responsible for the principal’s medical care. I am not entitled to any portion of the principal’s estate upon his decease, whether under any will or as an heir by intestate succession, nor am I the beneficiary of an insurance policy on the principal’s life, nor do I have a claim against the principal’s estate as of this time. I am not the principal’s attending physician, nor an employee of the attending physician. No more than one witness is an employee of a health facility in which the principal is a patient. I am not appointed as Health Care Agent or Successor Health Care Agent by this document.

Witness No. 1
Signature: ___________________________ Date: __________
Print Name: _______________________ Telephone: __________
Address: _________________________________

Witness No. 2
Signature: ___________________________ Date: __________
Print Name: _______________________ Telephone: __________
Address: _________________________________

(This portion of the document is optional and is not required to create a valid health care power of attorney.)

STATE OF SOUTH CAROLINA
COUNTY OF __________________________

The foregoing instrument was acknowledged before me by Principal on __________, 20 ______.

Notary Public for South Carolina __________________________
My Commission Expires: __________________________
Appendix E - Do Not Resuscitate Order

SOUTH CAROLINA
EMERGENCY MEDICAL SERVICES

RESUSCITATE

DO NOT RESUSCITATE ORDER

NOTICE TO EMS PERSONNEL

This notice is to inform all emergency medical personnel who may be called to render assistance to

(Name of Patient) that he/she has a terminal condition which has been diagnosed by me and has

specifically requested that no resuscitative efforts including artificial stimulation of the cardiopulmonary system by
electrical, mechanical, or manual means be made in the event of cardiopulmonary arrest.

REVOCATION PROCEDURE

THIS FORM MAY BE REVOKED BY AN ORAL STATEMENT BY THE PATIENT TO EMS PERSONNEL, OR BY MULTI-
LATING, OBLITERATING, OR DESTROYING THE DOCUMENT IN ANY MANNER.

Date

Patient's Signature (or Surrogate or Agent)

Physician's Name (Please Print)

Physician's Signature

Physician's Address

Physician's Telephone Number

DHSC 3442 (10/2009) SOUTH CAROLINA DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL
importance of Spirituality and Religious Beliefs

“Spiritual or religious strength sustains many people in times of distress.”

- Kagawa-Singer, JAMA, 2001; 286:2993
The Importance of Spirituality in African-Americans' End-of-Life Experience

Profound spirituality provided emotional and psychological support for most terminally ill African American patients.

Bedrock beliefs:

1. The providence of God and the divine plan for each person's life.

2. Intimate relationship to God expressed through prayer.

3. Almost all patients were willing to share their beliefs in long bedside interviews.

4. Willingness to share indicates that physicians can learn and validate the patients' spiritual sources of support.
CULURE AND DEATH

Many studies show African Americans prefer more life-support at end-of-life African Americans compared to whites:
  - Less likely to discuss EOL care with clinicians
  - Report lower quality of communication
  - More likely to feel discussing death may bring death closer
Appendix G

Five Stages of Grief

Elisabeth Kubler Ross

On Death and Dying

MACMILLAN PUBLISHING COMPANY

1969

Five Stages of Grief

1 - Denial

Denial is a conscious or unconscious refusal to accept facts, information, reality, etc., relating to the situation concerned. It's a defense mechanism and perfectly natural. Some people can become locked in this stage when dealing with a traumatic change that can be ignored. Death of course is not particularly easy to avoid or evade indefinitely.

2 - Anger

Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them. Knowing this helps keep detached and non-judgmental when experiencing the anger of someone who is very upset.

3 - Bargaining

Traditionally the bargaining stage for people facing death can involve attempting to bargain with whatever God the person believes in. People facing less serious trauma can bargain or seek to negotiate a compromise. For example "Can we still be friends?.." when facing a
break-up. Bargaining rarely provides a sustainable solution, especially if it's a matter of life or death.

4 - Depression

Also referred to as preparatory grieving. In a way it's the dress rehearsal or the practice run for the 'aftermath' although this stage means different things depending on whom it involves. It's a sort of acceptance with emotional attachment. It's natural to feel sadness and regret, fear, uncertainty, etc. It shows that the person has at least begun to accept the reality.

5 - Acceptance

Again this stage definitely varies according to the person's situation, although broadly it is an indication that there is some emotional detachment and objectivity. People dying can enter this stage a long time before the people they leave behind, who must necessarily pass through their own individual stages of dealing with the grief.
Appendix H

Universal Precautions

Acknowledgement of Understanding and
Practice of Universal Precautions

When you work in healthcare it is important to take precautions to prevent the spread of infection and disease. You need to protect yourself and the people you work for. Many diseases can be passed from one person to another, some more easily than others. One risk that healthcare workers face is exposure to blood borne pathogens. Three common blood borne pathogens are the Human Immunodeficiency Virus (HIV), Hepatitis B (HBV) and Hepatitis C (HCV). A vaccine is available to provide immunity against Hepatitis B. There is no approved vaccine for HIV or Hepatitis C.

A federal regulation, OSHA’s Blood Borne Pathogens Standard, is designed to minimize your risk of exposure to these diseases. Perhaps its most important requirement is what’s known as “Universal Precautions.” These precautions are designed to prevent transmission of blood borne pathogens. It means treating all human blood and other potentially infectious body fluids as if they are definitely infected with blood borne pathogens. Though the risk of infection is small, universal precautions help protect you from even that minimal chance.

Universal Precautions

Use Universal Precautions with Body Fluids that Could Contain Blood Borne Pathogens

These include:

- Blood (Wet or Dry)
- Semen or Vaginal Secretions
- Any body fluid visibly containing blood (such as saliva from bleeding gums)
Any body fluid you can’t distinguish from other body fluids

Additional body fluids (generally inside the body) that apply are: Cerebrospinal, Pleural, Peritoneal, Pericardial and Amniotic fluid. For example Pleural fluid is found in the lining of the lungs.

Universal Precautions do not apply to the following unless they contain visible blood:

- Feces
- Nasal Secretions
- Sputum
- Sweat
- Tears
- Urine
- Vomit
- Saliva

These substances do not carry the threat of blood borne pathogens unless they contain blood. However some of them do contain microorganisms that can cause other types of infection.

Always Follow Universal Precautions in Jobs and Tasks with a Risk of Exposure.

These may include:

- Transporting or handling blood and any contaminated or possibly contaminated materials including sharp objects, trash, laundry, etc.
- Cleaning areas that are or could be contaminated
- Working in an area or at a task where it’s unclear if there’s a risk of exposure to blood borne pathogens
- Contact with non-intact skin or body tissue.

What does it mean to “Use” Universal Precautions?
It is a prevention strategy in which all blood and potentially infectious materials are treated as if they are infectious, regardless of the perceived status of the source individual. In other words, whether or not you think the blood/body fluid is infected with blood borne pathogens, you treat it as if it is. This approach is used in all situations where exposure to blood or potentially infectious materials is possible. This means that you should follow the guidelines in situations where exposure may occur.

Probably the first thing to do in any situation where you may be exposed to a blood borne pathogen is to ensure you are wearing the appropriate personal protective equipment (PPE). For example, you may have noticed that emergency medical personnel, doctors, nurses, dentists, dental assistants, and other health care professionals wear protective gloves. This is a simple precaution they take in order to prevent blood or potentially infectious body fluids from coming in contact with their skin.

To protect yourself, it is essential to have a barrier between you and the potentially infectious material.

Examples of Using Personal Protective Equipment (PPE) as a Barrier against Infection. Include:

- Wearing gloves when you touch or handle potentially contaminated items or surfaces.
- Bandaging your cuts or broken skin

Additional examples most often seen in a hospital setting are:

- Using masks and eye or face protection with solid side shields to protect mouth, eyes, nose, and face from splashes, sprays, or spatters
- Wearing gowns, aprons, lab coats, and surgical caps when necessary to protect your body from splashes, sprays, and spatters
- Using shoe covers or boots if there’s a risk of exposure to large amounts of
blood or body fluids or possibly contaminated broken glass

Wear disposable gloves only once and replace them immediately if they're torn or contaminated. Remove all PPE when it's contaminated and before you go into a clean area or touch clean items. Remove contaminated PPE so it doesn't touch your skin.

Other important measures to reduce or prevent exposure to blood borne pathogens are: Practicing Good Hygiene and Eliminating Possible Situations for Exposure.

Examples of these include:

• Hand washing – this is one of the most important practices used to prevent the spread of infection!
• Wash with soap and water as soon as possible after removing PPE, contacting potentially infectious materials, or completing a Consumer procedure
• Flush eyes, nose, and mouth with water after body fluid contact
• Don't eat, drink, smoke, apply cosmetics or lip balm, or handle contact lenses where there's a risk of blood borne pathogens exposure
• Don't store food or drink in such areas
• Keep the workplace clean

Understanding Your Risk

The principal risk to the healthcare provider is in relation to a skin penetrating injury with a sharp object (such as a needle, lancet or broken glass) that has been previously contaminated with infected blood or other qualifying body fluid/material. Another is the splashing of infected fluid onto broken skin (such as a cut on your hand) or the splashing onto mucosa (such as the inside of your mouth, nose or in the eyes). These situations do not mean infection will definitely occur. They only identify the scenarios of greatest risk were infection might occur. It's impossible to know if someone is infected with a blood borne
pathogen just by looking at them, so it’s important to treat all the body fluids that can carry blood borne pathogens as if they are infected.

What to do if you are exposed?

If you are stuck by a used needle or other sharp object or get blood or other potentially infectious fluid in your eyes, nose, mouth or on broken skin:

1. Immediately flood the exposed area with water and clean any wound with soap and water or a skin disinfectant if available.
2. Then report the incident to your employer.

Points to Remember:

- Universal Precautions provide protection against Blood Borne Pathogens.
- To protect yourself, it is essential to have a barrier between you and the potentially infectious material.
- A vaccine is available for Hepatitis B.
- Handwashing is one of the most important means of controlling the spread of infection.
Appendix I

Volunteer Application

Heartland

Date: ____________________

Thank you for your interest in becoming a Hospice volunteer. The following information will provide us with a clear understanding of your abilities and interests and will help us to best channel your energies and capabilities. This information will prove most helpful in making volunteer assignments.

<table>
<thead>
<tr>
<th>General Information:</th>
<th>Are you over 18 years of age?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (Last, First, MI)</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Address (Street, City, State)</td>
<td>Telephone No.</td>
</tr>
<tr>
<td>Email Address</td>
<td>Cell Phone</td>
</tr>
<tr>
<td>Employer (if applicable)</td>
<td>Telephone No.</td>
</tr>
<tr>
<td>Occupation</td>
<td>Position</td>
</tr>
</tbody>
</table>

Briefly describe type of work you do: ____________________________________________________________

Have you ever worked for HCR Manor Care? ☐ Yes ☐ No  If yes, detail: ________________________________

Have you ever volunteered with Heartland Hospice before? ☐ Yes ☐ No  If yes, detail: ____________________

Total number of hours per week you could be available for hospice volunteering:

☐ Daytime  ☐ Evening  ☐ Weekend  ☐ Other

Education: (List those items which you believe could be helpful to you in hospice, i.e. schooling, work, lay experience, office skills, arts and crafts)

<table>
<thead>
<tr>
<th>Date</th>
<th>Type of Experience</th>
</tr>
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<tbody>
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<td></td>
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</table>

Personal Information:

Have you done any volunteer work? ________________________________________________________________

How did you hear about Hospice? ________________________________________________________________

Why do you wish to volunteer for Hospice? ________________________________________________________
**Personal Information (cont'd):**

Have you had experience with terminally ill people?  □ Yes  □ No  If yes, explain: 


Do you speak any foreign language?  □ Yes  □ No  What?

List any licenses/certifications you currently hold: 


Do you have transportation for your hospice volunteer work  □ Yes  □ No

What strengths do you bring to Heartland Hospice? 


**Areas of Interest:**

<table>
<thead>
<tr>
<th>Patient Related Services</th>
<th>Non-direct Patient Related Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Relieve Primary Caregiver</td>
<td>□ Hospice Office Work</td>
</tr>
<tr>
<td>□ Transportation</td>
<td>□ Mass Mailings</td>
</tr>
<tr>
<td>□ Meal Preparation</td>
<td>□ Fundraising</td>
</tr>
<tr>
<td>□ Write Letters</td>
<td>□ Hosting for Hospice</td>
</tr>
<tr>
<td>□ Homemaking Chores</td>
<td>□ Bereavement</td>
</tr>
<tr>
<td>□ Music Enrichment</td>
<td>□ Light Yard Work</td>
</tr>
<tr>
<td>□ Shopping</td>
<td>□ Babysitting for Hospice</td>
</tr>
<tr>
<td>□ Feeding</td>
<td>□ Volunteer's Children</td>
</tr>
<tr>
<td>□ Bereavement</td>
<td>□ Writing Letters</td>
</tr>
<tr>
<td>□ Light Yard Work</td>
<td>□ Telephoning</td>
</tr>
</tbody>
</table>

1. Have you ever been convicted and/or been found by a court of competent jurisdiction or a state agency of abusing, neglecting or mistreating patients or of misappropriating patients property in this state or in any other state? If so please describe the offense, the date and place of the conviction and the underlying circumstances or other information to help us evaluate your current fitness to become a volunteer.

   □ Yes  □ No

2. Have you ever been convicted of (1) felony, (2) cruelty to persons, or (3) assault of a victim sixty years of age or older? If so please describe the offense, the date of the conviction and the underlying circumstances or other information to help us evaluate your current fitness to become a volunteer.

   □ Yes  □ No

3. Have you ever been sanctioned by a healthcare licensing agency in this or another state or in any other United States or foreign jurisdiction? If so, please identify the nature and the date of the action, the licensing agency involved, and the underlying circumstances or other information to help us evaluate your current fitness to become a volunteer.

   □ Yes  □ No

"I hereby certify that I have not been convicted and/or found guilty of patient abuse, neglect, or mistreatment, or misappropriation of patient property in this state or in any state and that I am not listed in any resident or patient abuse registry in this state or in any other state. I understand that any offer to become a volunteer by Heartland Home Health Care & Hospice is conditional upon verification of this information with the state patient abuse registry and that a listing or such a registry or registries of any other state may act as an automatic withdrawal of any such offer to become a volunteer."

I understand that Heartland Home Health Care and Hospice requires a thorough background investigation for all potential volunteers. This investigation is limited to only that information required to determine fitness for volunteering and may include, but is not limited to: past employment history verification, job performance, disciplinary record, financial/credit history, and a criminal background investigation. By affixing my signature to this document I agree to hold harmless any previous employer, agent of that corporation, or any individual or organization providing information pursuant to this Authorization.

Signature of Applicant

In Case of Emergency:

Contact (Name) __________________________ Telephone No. __________________________

Physician __________________________ Telephone No. __________________________

Form # 4H-12035  [Date: 05/05, Rev. Date: 10/10] © 2010 HCR Healthcare, LLC
SELECTED BIBLIOGRAPHY

Berkowitz, Miriam C. “Moses meets Kübler-Ross: the five stages toward accepting death as seen in the Midrash,” Journal of Pastoral Care 55, no 3 (Fall 2001): 303-308.


Irion, Paul E. Hospice and Ministry, Nashville, TN: Abingdon Press, 1988


