

Lancaster Theological Seminary

The Opportune Time: The Role of Hospice Volunteers in Helping Patients Deal with Guilt,
Regret and Related Spiritual Issues at Ridge Valley Hospice

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by

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The Opportune Time: The Role of Hospice Volunteers in Helping Patients Deal with Guilt,
Regret and Related Spiritual Issues at Ridge Valley Hospice
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ABSTRACT

Hospice patients deal with a wide array of end of life concerns including deeply spiritual matters. Patients often reveal their personal struggles to trusted caregivers at opportune times. One member of the care team, the hospice volunteer, is often perceived as a trusted confidant. Therefore, volunteers are in a unique position to provide spiritual care. This study investigated the role and aptitude of the hospice volunteer regarding the spiritual care of hospice patients, focusing on matters of guilt, regret and forgiveness. Training volunteers to engage hospice patients in appropriate, healing ways is recommended, and suggestions for instruction presented.

DEDICATION

This work is dedicated to those who made it possible: The faculty and staff at Lancaster Theological Seminary, particularly, Dr. David M. Mellott, advisor; the congregation at Zwingli United Church of Christ, Souderton, PA, particularly Ms. Sue Wack; my wife, Dr. Sally Kuykendall, whose love, wisdom and encouragement were invaluable; our children, Eva, Emily, Matthew, Mark and Al for their enthusiasm and support for this endeavor; the Volunteer Coordinators at Ridge Valley Hospice for their wisdom, guidance, and passion for hospice care; *and especially* the volunteers at Ridge Valley Hospice, who work tirelessly to offer compassionate care to the patients they serve – I hope I have honored their voice

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Chapter I

Introduction

The explicit mission of hospice care is to provide holistic care to those at the end of life, offering specific attention to the physical, social, emotional and spiritual needs of the patient. Hospice care also offers support to the caregivers and the bereaved. In 2014, an estimated 1.6 to 1.7 million patients received hospice care, an increase of 20% since 2010 (“NHPCO’s Facts and Figures” 4). The number of those taking advantage of hospice services is likely to grow as the baby boomer generation ages, and as awareness of the quality of care and services provided by hospice and palliative care agencies increases.

After decades of research and anecdotal evidence from the hospice and palliative care fields, it is clear that patients deal with a variety of spiritual and existential issues at the end of life (Puchalski et al.; Woung-Ru; Yi-Jung). Indeed, Kenneth Doka reflects this concern when he argues that life-threatening illness is not only a medical crisis, but “is a psychological, social, and family crisis as well. Yet, even more than that, it is a *spiritual crisis* fraught with existential questions” (99 my emphasis). Disease and confronting one’s immanent death raises anxiety, disrupts human relationships and normal ways of coping and interacting with the world. Dealing with a terminal illness also has the potential to challenge cherished religious beliefs, one’s view and image of self, as well as provoke “questions about one’s relationship with the significant or the sacred” (Puchalski et al. 890). Since spiritual unease and distress often accompanies life-limiting illness it is cause for deep concern and attention, especially for those who offer care for those who are dying. In their article summarizing the findings of a 2009 Consensus Conference dealing with spirituality and palliative care, Puchalski et al. suggest that “spiritual distress or religious struggle should be treated with the same intent and urgency as treatment for pain or any

other medical or social problem” (891).

There are a myriad of spiritual and existential concerns that confront the hospice patient and their families. For example, those facing the end of life often engage in telling stories and life review, deal with meaning and purpose, confront grief and loss, and express anger and disappointment. Hospice and palliative care patients also deal with issues of guilt and regret and often seek reconciliation, healing and forgiveness.

“The Greek word for forgiveness is *aspheis*,” writes Vanier, “which means to liberate, to release from bondage; it means the remission of debt, guilt and punishment. It is used when the prison door is opened and the prisoner can go free. We humans are called to be free, to free others, to nurture life...” (135).

Basic to our humanity is this urge, this desire to be free. Yet, there are many obstacles to our freedom, some external and others internal, some critically important and others peripheral and less significant. This project will focus on guilt and regret as obstacles of deep importance and fundamentally connected to the spiritual wellbeing of the patient. When these feelings are left unattended they have the potential to undermine spiritual growth and prevent needed healing, leaving patients and caregivers alike in a state of brokenness and despair. However, guilt and regret can also serve a positive function, and when dealt with in healthy ways, can lead to a deeper connection to self, others and God, provide an awareness of the need for healing, and lead to reconciliation, forgiveness, or some other hoped for response or result.

Given the variety of spiritual issues that patients may face at the end of life, why focus on guilt and regret? After all, current research does not focus exclusively on these issues as the prime spiritual concerns of the patient or their families. However, studies indicate that patients and caregivers experience guilt and regret frequently and that the level of guilt or regret, as well

as the ability to deal in healthy ways with these feelings, can have a profound affect on a person's spiritual, psychological, emotional and even physical well-being (see Yi-Jung; Puchalski et al.; Kushner "Religious Resources for Healing;" Sanders et al.; Pickering and George; Planalp and Trost). Even though guilt and regret may not always present as primary concerns for patients and caregivers, they are key issues when dealing with grief and spiritual wellbeing at the end of life.

Guilt and regret, and the closely related emotion, shame, are serious issues that are of vital importance to our spiritual health and wellbeing, for they are deeply connected to issues of vulnerability, relationship, mystery and fear. The way we deal with guilt and shame will affect our lives and relationships, not only in the here and now, but also the way we perceive our ultimate destiny (Vanier; Kushner *How Good Do We Have to Be?*; Bell). Some believe the way we face and cope with guilt is our most fundamental concern as human beings (Westphal 69; G. Taylor 76; Rutledge *The Undoing of Death*). Perhaps this is why guilt is so difficult to deal with and is often avoided, denied, or buried deep in the recesses of our soul. Guilt and shame are often seen to be crushing and insidious, hidden deep in the crevices of our fear. Sometimes, unresolved guilt festers and becomes anger and bitterness. Often, guilt is misused, or is a tool for manipulation, which distorts our relationships with others and with God or a higher power. In other words, guilt may be at the root of our most pressing spiritual crises and appropriate diagnosis and treatment strategies are important for the hospice patient's care and spiritual health. Regret is also of critical concern, because such feelings are often misunderstood and lead to unnecessary suffering and diminished spiritual and emotional wellbeing (Cox). Given these deep spiritual concerns, it is important for hospice and palliative care agencies to give appropriate and concentrated attention to patients facing these issues at the end of life.

Spiritual care is a mandate for certified hospice organizations in the United States as stipulated in the Hospice Medicare Conditions of Participation (CoP). Since Medicare is the predominant source of funding and payment for hospice care in the U.S.¹, hospice agencies that receive Medicare disbursements must be certified by the Centers for Medicare and Medicaid Services (CMS). To be certified, agencies must comply with the Hospice Medicare Conditions of Participation. The CoP stipulates several key obligations regarding the spiritual care of the patient. First, certified agencies providing service for hospice patients must provide physical, psychosocial, emotional, and spiritual care for the patient and their families. With specific regard to the patient, such care must be done “in a manner that is consistent with accepted standards of practice...[and must] promote the hospice patient’s well-being, comfort, and dignity throughout the dying process” (“Medicare and Medicaid Programs” 32207, 32206).

The CoP also includes a stipulation that requires an interdisciplinary team to coordinate and provide care, a team that includes a registered nurse, doctor, social worker and *pastoral or other counselor* (ibid. 32206 my emphasis). Spiritual care includes, but is not limited to, a comprehensive spiritual assessment, a plan of care coordinated with others in the team, provision of services to meet the needs of the patient and family according to their religious practices and beliefs, and coordination of care with other local spiritual professionals (e.g., clergy, counselors) as needed (ibid. 32208).

Unfortunately, the CoP document does not give explicit instruction regarding the qualifications for the spiritual care worker other than the directive mentioned above, that care should be provided in a way consistent with accepted practice. Current research and hospice

¹ In 1982 Congress enacted the Medicare hospice benefit. In 2014, Medicare payments accounted for 85.5% of the payments for hospice services. Combined with Medicaid, the proportion of funding in 2014 was over 90% (“NHPCO’s Facts and Figures” 10).

related organizations are attempting to better define “accepted practice,” but regulations do not yet coincide with the emerging consensus regarding spiritual care (Puchalski et al.; “Medicare Hospice Conditions of Participation: Spiritual Caregiver”).

Given the lack of clarity and direction from the CoP, several questions arise regarding spiritual care for patients and best practices for such care. In their Consensus Conference report, Puchalski et al. draws our attention to these issues in the opening paragraphs:

Studies have raised critical issues including the need for a commonly accepted definition of spirituality, the appropriate application of spiritual care in palliative care settings, clarification about who should deliver spiritual care, the role of health providers in spiritual care, and ways to increase scientific rigor surrounding spirituality and spiritual care research and practice. (885)

This Doctor of Ministry project is motivated by a number of these concerns, and will focus on the role of hospice volunteers in delivering spiritual care, especially regarding the critical issues of guilt, regret and related spiritual issues. It is important, of course, to establish if volunteers should be involved at all in this aspect of patient need, a matter that is imbedded in the question intimated above, namely, “who should deliver spiritual care?” The following discussion will offer some attention to the prevailing research and wisdom regarding this query, as well as rationale advocating the critical role volunteers can play in providing quality spiritual care.

The National Hospice and Palliative Care Organization (NHPCO), a group that represents hospice and palliative care professionals and programs in the United States, advocates for highly trained spiritual care professionals to oversee and provide spiritual care, and suggests that these

“pastoral or other counselors” be certified chaplains.² However, there is recognition that some hospice care providers will not be able to meet this requirement. The NHPKO also does not want to suggest that a spiritual care provider “without these qualifications is incapable of providing spiritual care” (“Medicare Hospice Conditions of Participation”). Nonetheless, because of the specialized training required for certified (or board certified) chaplains, the NHPKO encourages their inclusion as part of the mandated interdisciplinary team (*ibid.*). The Joint Commission, which certifies and accredits health care organizations and programs, echoes this need:

The emerging prominent role of clinically trained, professional board-certified chaplains working with health care organizations in completing spiritual assessments, functioning as the “cultural broker,” and leading cultural and spiritual sensitivity assessments for staff and physicians can be of great value. Organizations that employ board-certified chaplains are able to focus directly on the significance and incorporation of cultural, spiritual and religious practices into the plan of care. (*qtd. in Puchalksi et al. 898*)

In other words, there are spiritual specialists³ who have acquired a particular skill set and specific knowledge that enhances the depth and sensitivity of spiritual care giving. Other research

² In commenting on the “Hospice Conditions of Participation: Core Services,” the NHPKO indicated that a “qualified and competent spiritual care provider” should be a chaplain certified in one or more of the following groups: The Association of Professional Chaplains (APC), American Association of Pastoral Counselors (AAPC), Association for Clinical Pastoral Education (ACPE), Canadian Association for Pastoral practice and Education (CAPPE), National Association of Catholic Chaplains (NACC), and National Association of Jewish Chaplains (NAJC).

³ The language of spiritual specialist/generalist was emphasized by the Rev. George Handzo and Dr. Harold Koenig or is now among common usage. This language will be important in discussion in Chapter 5 (Handzo and Koenig 1194).

strongly advocates for board certified chaplains as well to oversee, coordinate and provide spiritual care for patients and families (Yi-Jung; Puchalski et al.; “Medicare Hospice Conditions of Participation”).

Interestingly, there is no data on the number of chaplains, board certified or not, that serve as the primary spiritual care providers for hospice agencies. If the Conditions of Participation for hospice agencies do not mandate board certified or highly trained chaplains to fill the role of the pastoral or other counselor, then it is reasonable to suppose that a significant number of hospice organizations (of the 5500 in existence), for cost or other reasons, are unable to employ such an individual.

However, a hospice organization that does not include a board certified or highly trained chaplain on the team must still provide quality spiritual care as best it is able. At the very least providers of hospice care are required to meet the standards for the Conditions of Participation, even though such conditions are vague and open to interpretation. Furthermore, even if a hospice organization does employ a board certified chaplain, it would be impossible for such a clinician to serve all the spiritual and existential needs of every patient. In other words, quality spiritual care stretches beyond the contact of the patient with the chaplain or counselor. In recognition of these dynamics, education in a number of health care fields includes spirituality as part of the core curriculum (Puchalski “The Role of Spirituality...” 22-25; Puchalski et al. 889). Even though spiritual care is included in instruction for nurses, social workers and other health care professionals, such training is not at the level of the board certified chaplain.

Another important aspect of this discussion is the approach to care taken by hospice organizations. Hospice is oriented toward holistic care, meaning that equal attention is given to the physical, medical, social, emotional and spiritual care of the patient (“Medicare and Medicaid

Programs;” Sulmasy “The Healthcare Professional a Person” 105). For most hospices, there is an interdisciplinary team that is more expansive than the one mandated by CMS to provide care. The team includes nurses, social workers, physicians, spiritual counselors, home health aides, bereavement counselors, therapists and volunteers (“NHPCO’s Facts and Figures” 3). Although each member directs their care toward particular tasks within the realm of their expertise or responsibility, there is often an overlap of disciplines at a general or common level. For example, all team members should be aware of, and be able to assess at a basic level, the intensity of physical pain the patient is experiencing during a visit. Music therapists are trained in the art of their specialty, but nurses, social workers and aides will often sing hymns or favorite songs for the patient during routine visits.

In similar ways, all team members should be aware of spiritual distress or pain among patients and their families as well. In fact, members of the team other than the primary spiritual care provider often perform needed spiritual health interventions. For example, some physicians have prayed with their patients. Volunteers often read scripture or share stories of faith when appropriate and, as mentioned above, singing or humming a hymn is often a way for team member to comfort or connect with a patient.

Although team members may not possess the skills and knowledge to be a spiritual care specialist (or board certified chaplain), several studies have indicated that they should have basic training in order to have a deeper awareness of spiritual distress and concern. In fact, the Consensus Report advocates, “all members of the palliative care team should be trained in spiritual care. This training should be required as part of continuing education for all clinicians” (Puchalski et al. 900). The report goes on to specify the minimum content for the possible continuing education programs. Further, the training should be designed to go beyond, or

enhance, the initial introduction to spirituality a team member may have acquired in earlier curriculum and education for their area of expertise (see discussion above).

Of course, it may be asking too much for all team members to have training regarding spiritual issues and distress that may concern the patient. In some cases, limited contact, the tasks needed to be accomplished, or time constraints of the team member may hamper meaningful exchange regarding spiritual concerns (e.g., in the case of therapists, aides). However, it is important that those on the team with direct, sustained patient contact have some instruction or continuing education to deepen their awareness of patient spiritual care, or to help with decisions about when to refer to the chaplain or spiritual counselor. At the very least, those who provide frequent or every day care should have enough understanding of spiritual issues to ensure their treatment or care is not contrary to the patient's emotional or spiritual state and concerns. The same is true for those, like the physician or nurse, who are responsible for the overall management and direction of care.

However, training is also important because spiritual and existential concerns are not aspects of the person that can be, or should be, managed. The opportune moment for conversation or sharing about those matters that deeply touch the patient, or are of significant concern, are not predictable and often involves some form of relationship beyond a superficial level. In other words, one cannot, and should not, control when a patient will reveal spiritual concerns, or whom they may trust to share them. Besides chaplains or spiritual care providers, nurses and social workers are often members of the team entrusted with the meaningful questions and conversation that engage the spirit and faith of the patient.

There is another member of the interdisciplinary team that has consistent and frequent contact with the patient that is often ignored in the research and literature regarding spiritual

care. The typical hospice volunteer⁴, whose role is neither clinical nor professional, is often privileged, or in a unique position to experience the opportune time. Because the relationship between patient and volunteer has potential to go beyond the superficial level, a bond of trust may form that makes way for deeply personal conversations that touch on, or directly reveal, the patient's fears, faith, guilt, need for forgiveness, or other spiritual concerns.

Volunteers were instrumental in founding and supporting the U.S. hospice movement in 1974 and have been an integral part of hospice care in general since its inception in the United Kingdom ("NHPCO's Facts and Figures" 12; Block et al. 503; Morris et al. 428). After the Medicare hospice benefit took effect, which altered regulation and funding, there was a change in the proportion of professional staff to volunteers. Associated with this shift was a concern that volunteers would become less valuable or essential to hospice agencies (Block et al. 504). However, the role of the volunteer continues to be highlighted in hospice organizations. The Medicare conditions of participation stipulate that volunteers are to contribute "at a minimum, ...5 percent of the total patient care hours of all paid hospice employees and contract staff" ("Medicare and Medicaid Programs" 32211). Hospice agencies are the only health care provider to have such a requirement. NHPCO estimates that in 2014 there were nearly 430,000 volunteers that provided 19 million hours of service. Over 60% of the hours were spent with direct care (or spending time with patients and families), while the remainder of the time was offered to clinical care support and general support (including office work, fundraising, board leadership). Those volunteers that provided patient care "made an average of 20 visits to hospice patients"

⁴ There are hospice volunteers who provide services that require specialized education or training similar to or on par with professional hospice staff members. For example, some hospice agencies utilize volunteer chaplains, therapists and other health care workers who meet the standards of their profession, but who donate time to a local hospice. The typical volunteer does not have such training or expertise.

(“NHPCO’s Facts and Figures” 12).

Recently, there has been a trend toward less government support for Medicare, the principal source for hospice care funding. The adjustments in Medicare, other changes in the health care system, and federal budget issues have significantly impacted the delivery of hospice services (“The Medicare Hospice Benefit” 3). However, the needs for specialized attention typical of hospice and palliative care organizations and philosophy will likely increase as awareness of hospice services becomes more widely known and accepted, even if funding sources continue to decrease or are modified. If both trends continue – the decrease in funding and the increased need for services – then volunteers may become even more critical in the years to come.

The use of volunteers has historical and practical dimensions and certainly contributes a positive economic impact regarding cost for hospice care. But, mandatory volunteer participation is not simply due to historic or economic motivations and would not be required if it were detrimental to the mission of hospice and delivery of care. On the contrary, volunteers continue to be a vital part of providing effective care in hospice agencies.

Many hospice volunteers provide a variety of services regarding direct care of hospice patients and their families, such as visits, phone calls, writing letters, running errands/shopping, dressing and feeding patients, preparing meals, light homecare chores, and participation in developing basic aspects of patient’s plan of care (Worthington 19, Ridge Valley Hospice⁵ documents, Claxton-Oldfield and Claxton-Oldfield).

Research has shown that volunteer involvement in patient care is critical for a high

⁵ To protect confidentiality, Ridge Valley Hospice is a fictitious designation for the hospice organization involved in this study.

quality hospice program. One study has linked the amount of hospice volunteer hours and participation to higher quality of care ratings from bereaved families and positive reports from clinical staff regarding volunteer contributions (Block et al.). Volunteer involvement in other health care systems have been shown to influence higher levels of patient satisfaction, positive effects on their comfort level, especially in traumatic situations, and an enhanced sense of being cared for. Further, volunteer visits increase meaningful social contact, which can be critical for the patient's feelings of self-worth and purpose (Teasdale; Yi-Jung).

Volunteers are also to be a "listening ear" for the patient and family, which is of critical importance (Yi-Jung; Worthington 19-20). Puchalski reminds us, "Dying people are not always listened to - their wishes, their dreams, and their fears go unheeded. They want to share these with us" ("The Role of Spirituality" 5). In other words, a major role for the volunteer is to be an empathetic listener so that patients can express what is most meaningful to them.

Worthington also describes being a listening ear in other ways that demand a deep level of commitment and responsibility. She indicates that well-trained volunteers "can ask questions of medical personnel that family members or patients may be afraid to ask; help validate the feelings and emotions experienced during the dying process; and provide a support system when family and friends are unable to do so" (19). Although volunteers are not the experts (though some do have expertise in medical, psychological or spiritual disciplines), their role is a central one, and possibly of greater importance than recognized or generally acknowledged (Worthington; Planalp and Trost; Block et al.).

The various ways the volunteer interacts with the patient and their families allows for close relationships to develop and are, at times, of a different quality than that between patient and professional staff (Claxton-Oldfield, MacDonald and Claxton-Oldfield). One study echoed

what may seem a common sense reason for this unique relationship: that many patients deeply appreciate the volunteer choosing to offer valuable personal time to visit, help or simply listen (Teasdale). This gift of time, to a person suffering from a time-limiting illness, is invaluable.

Also, the duties and activities performed by the volunteer are often quotidian in nature, inviting the volunteer into the routine and familiarity of the day-to-day existence of the hospice patient and their families. The casual nature of this relationship may allow for ease of conversation and interaction that, along with the gift of time, has the potential to open doors of vulnerability and trust. While the patient may sometimes feel the need to be at their best when interacting with the professional staff, they are able to “let their guard down” with the volunteer, who may be seen as friend or companion.

Because of the nature of their role, the volunteer is often in a unique position that allows for observation and interaction with the patient and family distinctive from that of other hospice team members. Depending on their experience and length of service, the volunteer has also had a chance to observe a wide variety of relationships and ways of coping for patients and their families (Planalp and Trost 223). This familiarity and knowledge allows the volunteer to offer critical information and insight regarding the health and wellbeing of the patient. Worthington even suggests that, “patients may be more comfortable confiding in [the volunteer] rather than a member of the medical staff” (19). If this is the case, then volunteers are crucial liaisons between the patients and the rest of the interdisciplinary team (see also Claxton-Oldfield, MacDonald and Claxton-Oldfield).

The depth and breadth of what is communicated in the presence of the volunteers is certainly not limited to physical or medical issues. Planalp and Trost report that volunteers often observe challenges among patients and their caregivers or families that touch on a variety of

issues and feelings, such as fear, resentment, sadness and guilt (229). Further, spiritual concerns and reflection often bubble up from the ordinary and everyday and may not wait for the presence of the chaplain or spiritual care provider. This does not diminish the crucial role of the chaplain, but suggests a critical need for the volunteer to be trained regarding such concerns and issues. Learning necessary and appropriate skills will lead to greater awareness and the ability to assist the patient or pass along vital information to the spiritual caregiver. Although there are limitations on what the volunteer may be able to offer in terms of spiritual care, volunteers can play a vital role in this important patient need (Planalp and Trost; Yi-Jung; Worthington).

“We all struggle with issues of loss, meaning and purpose, suffering, and eventual dying,” Puchalski asserts. “In that struggle there is communion between all of us on earth. In that communion, the relationships and connections we form are the basis for partnership, help and healing (“The Role of Spirituality” 6). These connections and partnerships often form between the hospice patient and those uniquely privileged on the interdisciplinary team; and these relationships can indeed nurture healing, acceptance and the dignity of the dying patient. If a trust develops between the patient and the social worker, or chaplain, for example, significant sharing, especially concerning spiritual issues is possible. The volunteer is another member of the interdisciplinary team that has the opportunity to share on a meaningful level with the patient. Although they may not be the principal caregivers regarding spiritual concerns, their unique position and experience can impact help and healing, even with serious matters like guilt and forgiveness.

However, there is little research that has been done regarding the role of the volunteer in the spiritual care of the hospice patient. A search of over six hundred periodicals in several research data bases revealed only one article that considered intentional engagement of the

volunteer in spiritual care. In addition, there were few articles that focused specifically on guilt and regret, even when the literature surveyed pertained to other team members, like the chaplain or spiritual care provider.

Most of the research pertaining to volunteers focus on a number of areas, including, motivation for volunteering, demographic tendencies, personality traits, role, personal expectations, satisfaction, time spent volunteering, economic impact, boundary issues and diversity (see Morris et al.; Elliot and Umeh; Planalp and Trost; Worthington). However, research concerning volunteers is lacking in general, especially in areas pertinent to their role, like training and communication issues (Worthington; Dein and Abbas; Wittenberg-Lyles, Schneider and Oliver). Furthermore, as Elliott and Umeh assert “the types of psychological and other support volunteers currently provide to hospice patients and their families remain unclear” (377). Put another way, the impact and involvement of volunteers in the spiritual and emotional care of patients has been under-researched, if not ignored.

One of the issues related to research and discovery may be the lack of specific requirements regarding volunteer training. There are no federal requirements for specific volunteer instruction beyond the stipulation that training “be consistent with hospice industry standards” (“Medicare and Medicaid Programs” 32211). Studies give some insight into the industry standard, indicating that volunteer training curriculum typically includes instruction “that builds knowledge about hospice care and philosophy, develops attitudes of awareness and acceptability, and establishes team rapport among the training group. Volunteer training programs prepare patients for coping with patient care, ethical decision making, and clarify the volunteer’s role within the interdisciplinary team” (Wittenberg-Lyles, Schneider and Oliver 261). The NHPCO suggests a 16-hour training and offers standards for the orientation and

training of volunteers, guidelines that touch on 23 separate categories, including “psychosocial and spiritual issues related to dying” (“Regulatory Resources for Volunteer Managers”).

Even though there are guidelines about subject matter to be included for training volunteers, their tasks and responsibilities are broad and routine enough that training may not go into the depth necessary to deal with deeper issues beyond a cursory level. For example, several research articles suggest that current volunteer training is inadequate preparation for the serious communication issues that may arise for the patient like denial, fear, loss and guilt (Planalp and Trost; Worthington; Wittenberg-Lyles, Schneider and Oliver). To be fair, the NHPCO guidelines suggest that specialized training can and should be given to those volunteers who may perform functions and duties that go beyond the normal practice or typical basic tasks. However, there has been inadequate research, little guidance and few suggestions offered regarding training in critical areas like communication issues and spiritual care, especially concerning the volunteer’s interaction with the hospice patient.

This study, then, will give special attention to the role of the volunteer in assisting the patient with issues of guilt and regret and related spiritual issues. As mentioned in earlier discussion, guilt and regret, as well as forgiveness and reconciliation, are at the heart of a persons’ spiritual wellbeing. Although these are not the only spiritual concerns - and may not be the most important concern of all hospice patients - guilt, regret and forgiveness are of enough import that special attention should be given to these matters at the end of life.

Therefore, it will be critical to examine in this study whether volunteers have sufficient awareness of, or are able to effectively identify, concerns that are rooted in guilt and regret. In other words, do volunteers make appropriate connections between particular spiritual, emotional or psychological concerns and guilt, or shame, or a need for forgiveness? It will also be

important to determine how volunteers handle spiritual concerns that arise for the patient.

This inquiry will focus as well on recommended practices or education necessary for the volunteer to offer quality spiritual care, especially regarding guilt and regret and related spiritual issues. Further, suggestions of possible methods and strategies for establishing recommended practices will be given. Such training will focus on volunteers developing greater awareness and identification of guilt and regret, as well as helpful approaches when patients desire to grapple with these and related concerns.

Of course, the question “who should be involved in helping the patient to address these feelings of guilt, regret and need for forgiveness?” still remains. Is the chaplain or spiritual care provider the only qualified person that can offer the depth of assistance necessary with these issues, or is it possible for the volunteer to have some minor or significant role? If the hospice volunteer is to be involved, should all volunteers be trained or would it be helpful for the hospice organization to focus on specialized training for a small group of volunteers?

These and other questions will be examined through the lens of a particular hospice organization in southeastern Pennsylvania. Ridge Valley Hospice (RVH) is a not-for-profit hospice that serves patients in Bucks, Berks and Montgomery counties. Like any hospice, they are only able to care for patients diagnosed with six months or less to live and who are no longer receiving curative treatment. As is typical, many patients are on hospice for less than six months, though some have received hospice care for one or more years.

RVH typically serves a census of 68-75 patients and employs over 40 staff, including 22 nurses, three social workers and a full and part-time chaplain. 70 volunteers (of nearly 100) offer direct care to the patients. The patients, staff and volunteers associated with Ridge Valley Hospice are not very diverse ethnically or culturally - a very high percentage of patients are

white/Caucasian, primarily of European descent. RVH is also located in an area of Pennsylvania that has strong religious connections and traditions, which may influence discussions regarding guilt and regret as well as attitudes about forgiveness. The primary religious traditions are German reformed, Lutheran, Roman Catholic, Mennonite and Brethren, evangelical, non-denominational and what I term “unaffiliated as adults” (i.e., had a religious tradition/connection as child, youth or in earlier adult years).

For this project, the research will center on volunteers at RVH, with input collected through various methods (described in Chapter Three - Methodology). Although it would be helpful to gain insight from hospice patients, such research could be viewed as intrusive for someone dealing with the end of life. Hospice patients are also considered a highly vulnerable group requiring a significant level of human participation protection, which would be beyond the scope of this project. Research regarding hospice staff or others on the hospice team could also be valuable, but would also stretch the limits and focus required to give appropriate attention to the work of volunteers.

As stated before, the purpose of this study is to examine the role of the volunteer in helping patients deal with issues of guilt, regret and related spiritual issues, and to provide information to encourage specific practices and develop necessary training to enhance this role. Undoubtedly, attention to these concerns opens the door for a wealth of conversation regarding the spiritual care of the patient. For example, communication issues have already been cited as an important topic and is a subject connected to the matters being studied in this project. More attention will be given to this issue, as well as others that might arise from the research and results.

Another important matter that needs special attention involves the language used to

convey guilt, regret and forgiveness. Coming to understand the differing ways guilt or regret may be expressed is critical to helping the patient deal with these issues, and the way these feelings are verbalized may be different from the understanding or beliefs of the one offering spiritual care. Or, it may be the case that the patient will express feelings of guilt and regret, and the need for forgiveness, in ways different from their own religious tradition or culture.

One's spirituality and religious beliefs help to inform their feelings and responses to guilt and shame, as well as their attitudes about forgiveness. Although religion and spirituality are different concepts, they are also connected. As Doka asserts, "often, developmental outlooks, personal experiences and cultural perspectives will join with religious beliefs in shaping one's spirituality" (100). Even though each person's spirituality may be expressed and interpreted differently from another, even within the same religious community, it is also true that notions of spirituality and spiritual wellbeing are likely to be culturally bound (Tiew et al.; Ellis, Vinson and Ewigman). Guilt and forgiveness, then, will both reflect the religious culture and the individual spirituality of the patient.

At Ridge Valley Hospice, for example, the language used to communicate guilt and regret, as well as the need for forgiveness, will most likely reflect Christian culture and perspectives. However, it would be a mistake to assume that every hospice patient will express these issues in the same recognizable way, or even in ways that follow traditional Christian perspectives. In fact, more diversity may exist among the census at RVH than imagined due, not only to the different ways the religious communities represented articulate understandings of guilt and forgiveness, but also owing to each person's spiritual attitudes and values. If this is the case, then the religious and spiritual diversity among the patients served by Ridge Valley Hospice will give insight into needed study and thought regarding other populations and groups

(e.g., Jewish, Buddhist, “spiritual, but not religious”). Discussion concerning the language of guilt, regret and forgiveness will be given attention in the final chapter.

It is hoped that this project will offer knowledge and contributions to the conversation regarding the role of hospice volunteers and to hospice organizations regarding training and recommended practices pertaining to volunteers. However, the most significant point of this study is to enhance compassionate care for hospice patients facing the end of life. This is the purpose at the heart of hospice, and to be the aim of the volunteer, nurse, chaplain or any other hospice team member.

Chapter II

Literature Review

Initially it was important to determine whether guilt and regret were prevalent issues among terminally ill patients. If guilt and regret emerged as critical matters regarding the spiritual and emotional health of the patient, then the question of the role the volunteer had in helping address these needs became imperative. This is especially true for hospice agencies that, as a rule, employ a team approach and focus on holistic care.

Research from both palliative care and hospice care fields was consulted to gauge significance and refine direction for this project. Of course, helpful in this endeavor was discovering acceptable definitions of guilt and regret, ascertaining differences between them, and learning how these differences might influence avenues of healing and care. Articles and studies regarding forgiveness and other remedies would also be important for this endeavor.

A number of articles and manuscripts offered various ways of exploring and describing guilt and regret. Cox puts forward definitions of guilt and regret that clearly delineated the two. In order to offer appropriate treatment that would help the patient and their family, he believed it essential to “distinguish between guilt and regret. Guilt, as I am describing it,” Cox asserts, “is experienced when healthy persons violate their consciences.” He goes on to state that the feeling of “guilt signals that persons are out of spiritual alignment when they exploit others, betray confidences, or renege on promises” (64).

“Regret, on the other hand, is the feeling of sadness that accompanies choices that do not turn out as intended or that entail trade-offs among key values and ethical responsibilities” (ibid.). For Cox, there is no connection between fault and regret. In other words, there are those who have a misguided sense of guilt when the more appropriate term to describe their feelings is

regret. Understanding the difference can help the patient (or family member) let go of feelings misinterpreted as guilt. The distinction can also allow one to identify and embrace feelings of guilt in a healthy and more helpful way. He suggests ways of reframing the feelings of the patient or caregiver toward more proper understandings. Such reframing will lead to appropriate remedies and healing (see discussion 64-65). For example, Cox indicates that the “antidote for guilt is forgiveness” (65), while no antidote is given for regret. He implies that feelings of regret are important to acknowledge and let go, knowing that the agent has done the best they can.

Cox does indeed bring up a good point, but it is not clear that patients, family or others respond in the way he describes, or will feel set free by simply reframing the issue. Nor is it clear from research that such a distinction is helpful for those who misinterpret regret as feelings of guilt.

Other authors added perspectives that revealed a rich and varied approach to guilt. In fact, they focused specifically on guilt, offering scant attention or even silence regarding the feeling of regret. Using a phenomenological approach to religion and religious meaning, Westphal sets a high standard regarding the importance of guilt. His method is focused on a quest to show how religion “functions as a means for dealing with the fundamental human problems of guilt and death” (71) which he understands to be the “believing soul’s ultimate concern” (69).

Others expressed this attitude in both positive and negative ways (see G. Taylor; Rutledge; Bell). For example, in one of his sermons G. Taylor proclaims that Moses deals “with the profoundest question which can engage the mind and heart of humanity. He is talking here about sin and guilt and forgiveness” (76). Although some might argue whether this is the ultimate concern for humanity or our relationship to God, it does give insight into the profound

nature of guilt and how it is perceived in the world, especially by those who have been shaped by Christian values and culture.

For Westphal, there is an objective sense of guilt, tied to punishment, and the resulting feelings of fear and dread. Again, G. Taylor agrees: “We do not get away with anything in this world which God has created and which he has charged with moral accountability” (163).

However, Westphal indicates that the essential sense of guilt is an inner one, an inner awareness “of myself as less worthy of happiness than I would like to be.” (76). Such a move links guilt to a sense of unworthiness that arises when a person comes to agree, inwardly, with an outward judgment on his or her worth. Such judgments arise, of course, when a person acts in ways that would deserve some type of punishment, sanction or moral disapproval (Westphal 74-78). Bell echoes this notion succinctly in *Love Wins* when he speaks of those “haunted by sins of the past,” and a “deep-seated, profound belief that they are, at some primal level of the soul, not good enough” (171). G. Taylor would add that our unworthiness or guilt has less to do with particular sins or actions, but is more a state of our existence (164), or what some would call our “fallen nature.”

Vanier, in his experience, has witnessed many who are weighed down by guilt. He distinguishes between two types of guilt that are related to Westphal’s description, but differ in emphasis and direction. Vanier indicates that there is psychological guilt which “is induced in us by others, those who have made us feel that we are without value” (136). This type of guilt is also known as “shame” and is to be distinguished from moral guilt, “the one we induce in ourselves after having done something wrong” (136-137). Moral guilt arises when we hurt another person, commit a crime or take part in actions that cause damage to things or people. Psychological guilt, on the other hand, “is the feeling that can overwhelm us when we feel

rejected as individuals” (137), or as Rutledge expresses it, a “shame that crushes the spirit” (Rutledge *The Undoing of Death* 107).

Unlike Westphal, Vanier makes a distinction between a persons’ culpability for doing something wrong and claims about their worth, although “moral guilt and psychological guilt feed into each other” (137). This tangle is expressed in a compelling passage that gets to the heart of the guilt that many carry:

Mothers and fathers feel guilty because they are imperfect parents. Husbands and wives feel guilty because they do not know how to love and care for their partner. Perhaps we all feel guilty because we are not quite who we wanted to become; to that extent all of us are disappointed in ourselves so we disappoint others. (138)

Even though Vanier does not mention regret, he implies its presence in the feelings and thoughts that arise from this sense of diminished value or unworthiness. It is the complicated enmeshment between moral and psychological guilt and the disappointment (regret?) one feels that makes Cox’s reframing seem too simplistic. Yes, one may try to reframe feelings simply as regret, but a person may experience profound guilt (culpability, unworthiness) nonetheless.

In his book, *How Good Do We Have To Be?* Kushner echoes Vanier’s descriptions, but takes a different tact. He is concerned about the misuse of guilt and shame by religious people (and others) and how inappropriate or even manipulative use brings greater harm to individuals and society. He, of course, is “an advocate for religious life as a primary source of spiritual nourishment” (42), but hopes that such a life views guilt and shame in a way that promotes spiritual health.

At the root of our problems “is the notion that we are supposed to be perfect, and that we could expect others to be perfect because we needed them to be, [and these thoughts] leave us

feeling constantly guilty and perpetually disappointed” (ibid. 8). But, the feelings of guilt and disappointment have even deeper roots in our religious tradition. Using a conventional interpretation of the story of Adam and Eve, Kushner demonstrates that the traditional meaning of the narrative orients our humanity in a particular concept of sin. As a result, human beings are always imperfect before a God who deals severely with imperfection, and so, we are destined to live “lives...dominated by feelings of guilt and fear, guilt for the mistakes we have made, and fear for making yet another one” (ibid. 39). Kushner will name this view of guilt and shame as inappropriate, but recognizes that these beliefs are at the core of the conventional understanding and experience of these feelings.

Like Vanier, Kushner appeals to “psychologist’s” distinctions between guilt and shame: “Guilt, they say, is a judgment we pass on ourselves. It is a voice inside our heads telling us that we did something wrong. Shame is a sense of being judged by someone else.... Guilt is a product of an individual conscience.... Shame is the product of community” (ibid. 39-40).

Furthermore, Kushner claims that guilt can be connected to an illusory sense, deep within our consciousness, that we have control over all aspects of our lives and circumstances. Kushner cites Elaine Pagels, who asserts in her work *Adam, Eve and the Serpent*, that ““There is a human tendency to accept personal blame for suffering. *People often would rather feel guilty than helpless*. If the reason is moral rather than natural, we can persuade ourselves that we can control it”” (ibid. 13-14). Such an attitude or belief both challenges Cox’s simplistic view of guilt and regret, yet affirms the need to help people overcome this destructive illusion.

Although guilt and regret are often discussed in a negative vein, it is important to note that they were also viewed positively regarding spiritual, emotional and psychological health. Cox and Kushner were most explicit, indicating that a healthy sense of guilt and/or regret is

necessary for us to monitor our moral compass and behaviors. As “a colleague of [Kushner put it], ‘The purpose of guilt is to make us feel bad for the right reasons so that we can feel good for the right reasons’” (ibid. 40). Or, as Kushner observes, “if Man [sic] is the only creature that blushes, then a person who cannot feel shame...is less than completely human” (ibid.).

Each author mentioned had much more to relate concerning these issues, but suffice it to say that they provided a wealth of perspectives regarding guilt and regret, and how they are experienced by individuals and in society. Although there were similarities regarding these various points of view, it was evident that clean and neat definitions of guilt and regret are somewhat elusive.

Armed with this background material regarding guilt and regret, current literature was consulted to determine whether these feelings were of critical importance to those facing the end of life. Of course, there is an abundance of information regarding the needs of the hospice patient in the last stages of life. However, the importance of spirituality, ritual and other religious factors for the quality of life of the patient has been a more recent phenomenon, with greater interest and research emerging over the last few decades (Yi-Jung; Woung-Ru). Further research is being done as well in the related field of palliative care (Puchalski et al.; Pickering and George).

Most of the readings and survey instruments I encountered included issues of guilt and regret. Indeed, Puchalski et al. asserts that, “the regular assessment of spiritual and existential concerns is documented. This includes, but is not limited to, life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, *guilt, forgiveness*, and life completion tasks” (887 my emphasis). Although few studies dealt with these issues exclusively, the research indicates that patients experience guilt frequently, or see this as one of the prominent issues to

address when facing the end of life (Yi-Jung; Puchalski et al.; Kushner “Religious Resources for Healing;” Woung-Ru; Sanders et al.; Pickering and George; Planalp and Trost).

Woung-Ru and Sanders et al., in separate studies that focused on caregivers, indicate that issues of guilt and regret are of critical importance as well, not only when assessing the wellbeing of the caregiver, but how the caregiver’s spiritual and psychological health affects patient care or the patient/caregiver relationship. In fact, this relationship can have a profound influence on the patient’s ability to deal with issues of guilt and regret, since such feelings often arise from brokenness in relations with loves ones.

Another key issue for this study is the role of the volunteer in aiding the patient regarding issues of guilt and regret. Much of the literature focused on the role of professional clinical staff and their need to be attentive to, and trained to deal effectively with, spiritual issues of the patient (Puchalski et al.; Woung-Ru; Cox; Pickering and George). Only one article focused specifically on the volunteer’s role in spiritual care of the patient. Yi-Jung offers the premise that religious volunteers do have something significant to offer. Volunteers are able to provide critical emotional support, offer a compassionate and listening ear, educate about religious themes and to pray, read the Bible and sing hymns. However, because “volunteers lack the professional, theological, religious and counseling training and authority to administer the sacraments...they cannot, therefore, provide [the] in-depth spiritual and religious services” (720) that can be provided by qualified chaplains and other religious professionals.

Another limitation mentioned by the patients in this study regarding religious volunteers was the issue of religious authority. For some, the perception that “divine power ...[was] only given to the ordained minister by God” was a reason for this greater sense of religious authority being granted to chaplains and clergy (717). Also mentioned was the possibility for harm by

volunteers due to lack of training or accountability, though “this study did not discover any unexpected harm to patients...” (720).

The author indicates that in spite of these limitations, and in light of the absence of adequate numbers of chaplains, the care of the “religious volunteer” is better than “no such care at all” (709). In fact, the article indicated clear evidence that the religious volunteer plays an important role in providing holistic care for the patient.

Many studies highlighted the role of volunteers as critical members of the team that provides holistic care for patients with life-limiting illnesses (Yi-Jung; Elliot and Umeh; Block et al.; Planalp and Trost; Morris et al.; Dein and Abbas; Wittenberg-Lyles, Schneider and Oliver; Worthington). In fact, volunteers must provide five percent of direct patient care for hospice programs certified by Medicare (“Medicare and Medicaid Programs” 32211). Even though volunteers are seen as vital members of palliative and hospice care teams, they have been an under-researched group. As a result, the exact nature of their role in the care of the patient, especially regarding spiritual and emotional concerns, is not clear or known (Dein and Abbas; Wittenberg-Lyles, Schneider and Oliver; Elliot and Umeh). A number of studies suggest that volunteers are underutilized, and with proper training can provide critical “services beyond those usually offered....” to support patients and families (Worthington 19; Planalp and Trost; Wittenberg-Lyles, Schneider and Oliver).

Puchalski et al. are especially resolute concerning the positive and necessary role of clinical staff and the palliative care team in the spiritual care of patients. These authors advocate a disciplined strategy or plan addressing the spiritual wellbeing of the patient that includes a team/coordinated approach overseen by a board certified chaplain. Although this report offers multiple recommendations regarding program, education and the need for further research, they

fail to highlight volunteers and their role in this process.

It is clear from the research, then, that training is necessary for those who offer attention to the spiritual needs of the patient. Although the chaplain or other religious professional may provide or oversee care, a number of studies promote some form of education for clinicians, staff and volunteers regarding the emotional and spiritual wellbeing of the patient. It is also clear that more research needs to be done regarding volunteers and their role in the spiritual care of the patient (Sanders et al.; Woung-Ru; Yi-Jung; Worthington; Wittenberg-Lyles, Schneider and Oliver; Planalp and Trost).

In “Religious Resources for Healing,” Kushner indicates, “there are two things which scare the seriously ill more than the prospect of dying. One is pain and the other is loneliness, abandonment. People are not afraid of dying, they’re afraid dying will hurt” (4). This echoes wisdom gained by those who work with terminally ill and dying patients. However, although relief of pain and offering a caring presence is critical for hospice and palliative care patients, there are other possibilities that may aid in transformation, healing and spiritual wellbeing. For example, Puchalski et al. list twenty-three “spiritual health interventions” for the palliative care patient, including journaling, breathing practice, meditation, listening to the patient’s story, and sacred/spiritual readings or ritual (895).

The literature spotlights several other avenues for healing and finding a sense of peace, especially concerning issues of guilt and regret. Pickering and George speak of open and honest communication as being key. Such communication can aid the patient in the dying process and also helps prevent “years of avoidable guilt, regret and sadness” for loved ones (334). Vanier and Kushner also emphasize the importance of healthy and appropriate communication, while several authors underscore the value of staff and volunteers being compassionate and empathetic

listeners (Vanier; Kushner “Religious Resources for Healing;” Puchalski et al.; Yi-Jung; Worthington). In other words, even though attentive listening and earnest conversation will not bring a physical cure, such approaches can have a profound affect on the spiritual health of the patient. Unfortunately, as some studies indicate, training in appropriate and effective communication skills is lacking, especially for volunteers (Planalp and Trost; Worthington).

Since abandonment or loneliness is a significant concern for the patient, it is not surprising that community is essential when confronting the end of life. For example, Sanders et al. and Puchalski et al. indicate that support groups for the patient (in palliative care) and caregivers are vitally important. Yi-Jung claims that religious volunteers help provide emotional support for patients, help patients maintain self-respect, and assist with “improving social contact and community relationship” for the patients they attend (715-716).

“A Rwandan proverb says, ‘To go fast, walk alone. To go far, walk together’” (Katongole and Rice 20). Defining community is not a priority for this study, though the proverb gives us an intuitive grasp of what “community” entails - walking together. In almost every article, some form of walking together was implicit and involved communication, listening, planning, serving, helping, conflict resolution, reconciliation, and companionship on the journey.

Other key elements to dealing with the spiritual wellbeing of patient, especially regarding guilt and regret, are the role of faith, spiritual practices and ritual. In “Religious Resources for Healing”, Kushner claims, “even as we accept death, we have to recognize the chaos it represents...Ritual is one of the ways we deal with chaos. Ritual is a way of making the future predictable” (3-4). Others mentioned the importance of faith or spirituality for all those involved with end of life or long-term care. Puchalski et al., Yi-Jung and Kushner focus on the spiritual and religious needs of the patient. Although each may offer a variety of views of how that care

is given or who administers spiritual care, it is clear from years of research that religion, spirituality and faith are essential to the overall wellbeing and health (spiritual, psychological, emotional) of the patient. Just as critical is the need for persons (staff, volunteers) willing to help the patient cope with spiritual issues.

Yet, the ability to assist with such issues requires preparation and reflection on the part of those who may offer care to the patient. Helsel, in an article that addresses grief work for chaplains, and Jones, a clinical social worker, focus on faith and ritual for staff that work with hospice or terminally ill patients. Each acknowledges the emotional and spiritual toll that staff often contend with and offers specific ways and rituals to aid the staff persons healing and spiritual wellbeing. Helsel describes the importance of memorial services, meditation time and the Lord's Supper as ways to find healing and to deal with loss (340-341). Jones offers possibilities for hospice staff to find balance, perspective and even peace. She suggests journaling, support groups, and paying attention in various ways to ones physical, emotional, relational and spiritual health (40-41).

When taken together, the articles suggest that all those experiencing the end of life, or providing end of life care, are vulnerable to the intense emotions, questions, and challenges that arise when facing death. Kushner warns, "what we need to remember is how chaotic, how chaos producing death is, so that we never quite come to accept it as normal" ("Religious Resources for Healing" 4). No healthy person, no matter how professional or strong, is immune from the disorder and turmoil that often accompanies dying. Although death and dying can leave us vulnerable, wounded and disorientated, we do our best to bring peace, healing and dignity to the process. This process is at best a journey, a "walking together," and usually includes faith, religious meaning, and ritual.

Finally, forgiveness was also mentioned as critical for healing, spiritual wellbeing, and peace. As stated earlier, Cox makes clear that forgiveness is the “antidote for guilt” (65). Puchlaski et al., list “reconciliation with self and others” as one of the spiritual health interventions for palliative care patients (895). Of course, forgiveness is a first step, or at least the most critical one, when seeking reconciliation. Closely connected to forgiveness, for some patients, is a profound sense of God’s care and acceptance (Yi-Jung; Kushner “Religious Resources for Healing”). As one hospital patient remarked to Kushner on a visit, “...no matter what a mess you’ve made of your life, you haven’t estranged yourself from the love of God” (“Religious Resources for Healing” 11).

“Forgiveness,” Vanier asserts, “begins when we become aware of our fears and barriers” (150). Seeking forgiveness from a loved one, one’s self, or from God – or offering forgiveness to others – is also a journey that is a difficult one, fraught with entrenched attitudes, brokenness and fear. Yet, as Vanier suggests, it is basic to our humanity to seek forgiveness, to seek to be free, to free others and to nurture life around us (135). Although it may be odd to speak of nurturing life when dealing with the end of life, it is one of our most important tasks. Indeed, as Vanier declares, “forgiveness is to begin to love and accept ourselves, trying to understand and appreciate all that is valuable in us all, praying that what blocks us all from being free may break like a dam, so that what is most precious in us may flow forth” (162).

If the hoped for outcome of one’s (caregivers, staff, volunteers) striving with those who are dying is to aide, even in a small way, the flowing forth of what is most precious in us, then such work is indeed necessary, noble and sacred.

Chapter III

Methodology

This project utilized qualitative research as the primary mode for discovery and analysis. Qualitative research is oriented toward understanding and meaning, and “cultivates the most useful of all human capacities: The capacity to *learn*” (Patton 1). The researcher can make use of several qualitative methods and approaches for such learning. In this case, a phenomenological approach was employed to ascertain and examine the desired data and information.

Phenomenology was introduced by the philosopher Edmund Husserl (1859-1938) and has been used to describe a variety of methods and ways of understanding reality for social scientists, philosophers and other researchers. Although it does not have a single definition or use, phenomenological inquiry typically focuses on the lived experience of the participants in the study. It aims to discover common themes or essences of the experience being investigated and attempts to give rich description to explain, interpret and express meaning. Phenomenological inquiry makes use of methods like in-depth interviews or direct participant observation to explore what meaning or interpretation participants give to images, values, practices or beliefs regarding a particular experience (Patton 104-107; Sensing 56).

Even though phenomenological inquiry was key, the research for this project did not use an exclusively qualitative approach, or even a single method. Swinton and Mowat argue, “it is our opinion that the most effective way that practical theologians can use qualitative research methods is by developing a an eclectic and multi-method approach which seeks to take the best of what is available within the accepted modes of qualitative research, but is not necessarily bound by any one model” (50).

Therefore, a mixed-method approach was used to discern the extent hospice volunteers at Ridge Valley Hospice paid attention to, or recognized issues of guilt, regret and related spiritual issues among the patients they served. Several approaches also focused on discovering the level of comfort volunteers had in dealing with these issues. A portion of the research was completed as part of a directed study and involved a literature review and needs assessment, which included interviews with key informants and the development of a survey for volunteers at RVH. Initially, this work was simply for the purpose of aiding Ridge Valley Hospice with volunteer concerns and training and was not to be generalized.

EPOCHE

Part of the qualitative research process is the need of the researcher to reflect on personal biases or perspectives at various points in the study, especially in the initial stages. Biases can affect approaches, methods and analysis. One of the critical aspects of this project entails the definition of guilt and regret, and my preliminary understanding was rather basic. My initial view included the sense that it was possible to feel regret without feeling guilty, but that the feelings of guilt implied regret (at least for those who were relatively healthy psychologically and emotionally). For me, guilt is an inward feeling that arises from doing something wrong, or having actual or *perceived* culpability for an event, action or circumstance. Regret describes feelings that arise when a person wishes that something had not taken place or had happened differently, whether a person was at fault or not. In my initial view, guilt and regret were different, but could be connected. Also, there was little nuance in my understanding of either guilt or regret.

Another bias concerned the relationship between the patient and volunteer. On the one hand, I believed insufficient attention was been given by volunteers to guilt, regret and related

spiritual issues for the patient. On the other, I supposed patient/volunteer relationship to be multi-faceted, and that issues regarding spirituality would be readily discussed, depending on the trust level between patient and volunteer. Put another way, although the volunteer's ability to recognize or deal with particular issues might be limited when compared to a chaplain or spiritual counselor, I believed volunteer/patient conversations delved beyond the surface, and dealt with more than simply upbeat, cheerful subjects. I did not believe that volunteers or patients would be resistant to deeper, and even more difficult matters.

RESEARCH COMPONENTS AND METHODS

Literature Review. To address the questions at the heart of this project, and uncover related issues, it was important to consult the literature regarding guilt and regret and related spiritual issues among terminally ill patients and their caregivers. I decided to give concentrated attention to current articles and evidence-based approaches touching on research with hospice care, palliative care, volunteers, spiritual assessment, spiritual care and guilt/regret. Literature that focused on remedies, or ways of dealing with guilt and regret, and recommended practices that would promote spiritual health, was also consulted. Since there was very little research regarding the volunteers' role in spiritual care of the patient, articles focusing on the role of palliative care and hospice staff in the spiritual care of the patient were reviewed.

Key Informant Interviews. Another element of discovery involved interviews with a small sample of key stakeholders connected with Ridge Valley Hospice. The purpose for this task was to explore issues of guilt and regret that often arise at the end of life. The interviews aimed at providing opportunities for people to share their thoughts and perspectives, and to evaluate what

might help other volunteers at RVH. Interviews, especially with key stakeholders, are a critical aspect of phenomenological research. Interviews give the investigator a chance to ask specific questions regarding the lived experience of the interviewee, as well as an opportunity to ask follow up questions to provide depth or to examine layers of meaning.

I conducted five interviews, three with RVH volunteers, one with the Volunteer/Bereavement Coordinator at RVH, and the last with the Director of Pastoral Services/CPE Supervisor at a nearby behavior health organization. The Volunteer/Bereavement Coordinator chose the volunteers that were interviewed, based on several criteria. I requested she choose volunteers who were involved with direct patient care, had been with RVH for three or more years, and were not volunteer chaplains.

The interviews were limited to 45 minutes (approx.) in duration. Two interviews occurred at the offices of Ridge Valley Hospice and two at the interviewer's place of employment (a local church). The meeting with the Director of Pastoral Services took place in his work office. All interviews were conducted in locations that preserved confidentiality and ease of conversation. They were recorded via a digital recorder and stored on a password-protected computer. The participants were asked to sign a basic consent form and made aware that results could be used to provide direction for training hospice volunteers at RVH. The interviews occurred between July 5 and July 23, 2013.

The interviews were guided by questions that explored interviewees' perception of guilt and regret among patients, caregivers, staff and fellow volunteers. The questions were reviewed and the professor guiding the directed study offered suggestions for revision. Although the research focus primarily involved the perceived feelings and needs of the patient, feelings of guilt and regret among caregivers, volunteers or health care providers were also a concern. It

was recognized that such feelings among those who offered care could influence the patient's comfort level with regard to revealing and confronting their own guilt and shame, as well as their comfort seeking remedies for healing. There was also an initial concern to investigate the care of the caregiver as a possible route for investigation. Due to the difference in experience and role, especially between the volunteers and professional staff, a few different questions emerged for the Volunteer Coordinator and Director of Pastoral Care.

Extensive notes were taken using the recorded interviews and the data was analyzed for major themes and ideas. The data, themes and ideas were confirmed through two subsequent examinations of the recordings. The results were presented to the Volunteer/Bereavement Coordinator to discuss findings. After this discussion, the literature and interview results were consulted as direction for a survey to be given to all eligible volunteers at RVH.

Survey for Ridge Valley Hospice Volunteers. The next phase of this project involved the creation of the survey as a way to further explore RVH volunteers' interaction with the patients and caregivers regarding guilt and regret and other issues that had potential spiritual import. It was also part of the needs assessment with results of the survey to be matched with findings from the interviews. Further, the survey was designed to reach and gain input from a greater number of volunteers as an aide to the investigation and purpose at hand.

Though the literature review and interviews produced a number of common themes and questions that could be used for the survey, several questions emerged from the interviews as guiding principles: (1) Do Ridge Valley Hospice volunteers believe that issues of guilt and regret are prevalent among patients and caregivers? (2) Are the volunteers able to make the appropriate connections between particular spiritual, emotional or psychological concerns and guilt and

regret (e.g., do they see that some spiritual or emotional issues are grounded in feelings of guilt)? (3) How do the volunteers handle spiritual (or other) concerns that arise for the patient? Are these concerns communicated to the staff? (4) What is the role of friendship (between the volunteer and patient, or caregivers), and does this impact the overall health and spiritual wellbeing of the patient or caregivers.

A number of articles consulted for the literature review used or included instruments developed to measure spiritual wellbeing and quality of life (Sanders et al.; Woung-Ru; Puchalski et al.). Many of these assessment tools mentioned incorporated questions regarding guilt and regret and other spiritual concerns. From these examples I researched eight assessment tools. Of these, four instruments were chosen as guides for the development of the survey, especially with regards to design, scoring, formatting and ways of asking questions (“Brief COPE;” Ellison and Paloutzian; Marwit and Meuser; “Social Support Survey: RAND Medical Outcomes Study”). The questions and format for the survey were reworked several times and submitted as part of the directed study. The survey was again reviewed for consistency and clarity and pilot tested by the Volunteer Coordinator and Manager at Ridge Valley Hospice. After the review and pilot test minor changes were made. The survey (Appendix A) used a four point Likert scale and was formatted to encourage the highest possible response rate.

Ridge Valley Hospice has 102 volunteers, though some are inactive. There were 93 active volunteers including three volunteer chaplains. Surveys were sent to all active volunteers except the volunteer chaplains. In all, 90 surveys and return envelopes were mailed to RVH volunteers in early November 2013 along with an introductory letter from the Volunteer/Bereavement Coordinator and a letter from the researcher explaining the survey, and indicating that completion of the survey was voluntary. The requested deadline for completing

the survey was November 25, 2013, though surveys were collected through the first week of December. Responses were anonymous and participants were invited to take part in a focus group that would discuss the findings. All surveys were returned to Ridge Valley Hospice and initially collected by the Volunteer/Bereavement Coordinator to ensure confidentiality.

The results were tabulated by frequency of response and major themes and ideas were highlighted. The results from the survey were compared to the themes and ideas from key informant interviews and presented to the Volunteer Coordinator. It was then decided to proceed with the development of specific research designed to focus on the research questions for the D.Min. project.

RVH Volunteer Focus Group. A key element of this project involved meeting with a focus group that discussed issues based on the findings from the literature, interviews, survey and consultations with the Volunteer/Bereavement Coordinator at Ridge Valley Hospice. The focus group is another method designed to gather first hand information about the experiences of participants (RVH volunteers). Although focus groups do not allow for as much in-depth discovery from individuals as in interviews, they do permit interaction among group members. Such contact and communication allows for easier comparisons between group members and “the ability to give the group control over the direction of the interview....” (Morgan 11; Morgan’s discussion regarding focus groups 7-18). Such “control” can be critical to discovery of actual experiences of the participants without the group being overly burdened by the researchers agenda or desire for specific results. Of course, the ability of the researcher to facilitate such a discussion is key.

Since this aspect of the research involved collecting data from human participants that

would possibly be used to contribute to generalizable knowledge, and which would potentially report individual participant activity and identifying information, it was necessary to gain approval for the research from the Institutional Review Board (IRB) at Ridge Valley Hospital.⁶ Ridge Valley Hospice is part of the Post Acute Care Services of the hospital. The application for IRB approval was submitted to the board on February 5, 2014. The researcher also completed and passed the National Institute of Health's training course, "Protecting Human Research Participants" on February 13, 2014. After meeting with the IRB, the research was approved on February 14, 2014.

After IRB approval, participants were recruited. Participants for the focus group were selected from a pool of volunteers who completed the survey and expressed interest in this subject matter. Focus groups of 8-10 participants were to be formed based on eligibility and availability. The process of choosing, and passing along names, of prospective focus group participants was handled by the Volunteer Coordinator at RVH.

There were a few limitations regarding who could take part in the group. Participants needed to be volunteers with Ridge Valley Hospice that (a) had at least three months experience, and (b) were currently designated as being on active status. The researcher also had a preference that participants in the focus group were currently seeing patients. As with previous methods, volunteer hospice chaplains were excluded from consideration.

Contact was made with potential focus group members by phone to further gauge their interest and availability. Eight of the nine candidates were selected for the group and further calls were made to determine an initial meeting time and to ask for contact information. A separate call was made to coordinate timing for the first focus group meeting. An initial letter

⁶ To protect confidentiality, Ridge Valley Hospital is a fictitious designation.

and consent form were emailed individually (i.e., not in a group email) to the participants.

The focus group meetings were held at Community United Church of Christ⁷ in a room that could comfortably accommodate the focus group, preserve confidentiality, and promote ease of conversation. Refreshments were provided at each group meeting. The meetings were recorded via a digital recorder and stored on a password-protected computer. A note taker was on hand to record pertinent information from the discussion.

At the first meeting the group members were informed of their rights as research participants and were asked to sign a consent form (Appendix B). The focus group met three times for approximately an hour and a half for each session. At the start of each focus group participants were reminded to protect patient confidentiality and not use the names of patients they cared for. Focus groups included questions to explore their exposure to issues of guilt and regret (and related spiritual issues) among hospice patients and caregivers. They were also queried regarding their response to these issues and comfort level dealing with spiritual concerns. The initial questions for the first two sessions are listed in Appendix C. However, the researcher pursued new ideas as they emerged in discussion among the focus group participants. The questions for the third meeting were developed after the first two sessions in order to focus the dialogue and research. The meetings occurred between March 25 and April 22, 2014.

Extensive notes were taken using the recorded sessions and compared with observations from the note taker. The data was analyzed for major themes and ideas. The data, themes and ideas were confirmed through two subsequent examinations of the recordings.

Follow Up and Additional Consultation. After the focus group, I consulted additional literature

⁷ The name of the church has been changed to protect confidentiality.

regarding hospice volunteers. Two follow-up sessions were also conducted with the Volunteer/Bereavement Coordinator on May 15, 2014 and June 17, 2014. These meetings dealt with questions and issues that arose during the focus group sessions as well as other pertinent information concerning RVH. Notes were taken during conversations.

Outside experts were also consulted regarding the research and contacted by email. After initial responses, a face to face meeting and interview was scheduled with one of the professionals, Mary Martha Thiel, a chaplain with over 30 years experience. Rev. Thiel has spent much of her career dealing with end of life issues and care. The meeting occurred on September 26, 2014 at an agreed upon location that allowed for ease of conversation and confidentiality. The meeting was recorded via a digital recorder and stored on a password-protected computer. The content of the interview was oriented toward a variety of issues critical to the research.

EMERGING THEMES AND DATA TRIANGULATION

Qualitative analysis requires a careful examination and analysis of the data (extensive and detailed notes of conversations, discussions from interviews, focus groups) by coding for *a priori* themes as well as emerging themes. *A priori* themes included guilt, regret, forgiveness and spirituality. Emerging themes came to light through examination of the data. Such assessment led to the discovery of major themes and ideas that corresponded to the experience of volunteers, and uncovered connections that would reveal meaning and interpretation.

The mixed method approach used for this project was also helpful in a critical way. It allowed for triangulation of the data from the different methods, a technique important in qualitative research. As Sensing asserts, “triangulation provides a complex view of the

intervention enabling a ‘thicker’ interpretation. It is a way to cross-check your data that provides breadth and depth to your analysis and increases the trustworthiness of your research” (72).

Triangulation permitted a chance to test the consistency of the results as well as discover differences. This practice offered the opportunity for deeper insight concerning the role of hospice volunteers in delivering spiritual care, especially regarding the critical issues of guilt, regret and related spiritual issues.

RESEARCH METHOD LIMITATIONS

Although the research methods employed were valuable for discovering meaning and important wisdom regarding the hospice volunteer’s role in the spiritual care of the patient, it is important to note that such research methods certainly had possible limitations. First of all, the interview process depends on good questions and follow up that elicit appropriate responses that accurately reflect the research problems and issues. Also, since the interviewer/researcher controls the process, it is possible that the interviewer’s agenda can unduly influence responses given or ignore important matters that could affect the research. Lastly, the information given in separate interviews are subject to the researcher’s bias, which may have an affect on comparisons made between interviews as well as themes extracted from the information gathered. However, considering preconceptions and feelings before interpreting results can lessen the effects of possible bias. Further, giving voice to the participants through direct quotes and careful reflection of ideas can also minimize such impact.

Similar issues can affect focus group results, such as the influence of the researcher’s bias and the need for good initial and probing questions. In fact, suitable probing or follow up questions are even more critical for focus group. Other issues can also influence the focus group

results. First of all, the researcher's ability to facilitate, rather than direct, the discussion is crucial. Since there is limited time for focus group interaction and discovery, the ability to stay on topic is critical as well. Being too directive or too detached could affect, or even undermine helpful results. Finally, research using focus groups is best when the researcher can compare results from two focus groups. In the case of this project, the number of participants allowed for only one focus group, which can make it difficult to ascertain if results from this group truly reflect the attitudes and experiences of the other volunteers at RVH (see discussion of focus groups in Morgan 7-22, 44; Sensing 120-124). Hopefully, the triangulation of results with the other two methods was useful for ameliorating this limitation.

Another drawback in the research concerned the survey. Some of the survey questions did not distinguish between the volunteers' interaction with patients and caregivers, since this was part of the needs assessment and discovery phase. However, it was evident in the interviews and focus groups that the volunteers' role is almost exclusively patient centered, especially regarding conversations and discussions of a personal, spiritual or sensitive nature. In fact, unless directly asked, the volunteers seldom spoke of a relationship with the caregivers. Therefore, it was presumed that the survey reflected volunteer/patient interaction and relationship.

Despite possible limitations, the methods used were valuable ways to gather information and data concerning Ridge Valley Hospice volunteers and their role in helping patients cope with spiritual matters, especially those of deep significance like guilt, shame and forgiveness. The results and a brief analysis of emerging themes are presented in the next chapter.

Chapter IV

Results and Major Themes

KEY INFORMANT INTERVIEWS

The key informant interviews were important in the initial discovery phase. The primary function of the interviews was to explore the informant's experience regarding exposure to matters of guilt and regret among patients, caregivers, staff and volunteers. The interviews were also conducted to discover other important themes and issues that impacted or were connected to the primary task. The key informants were from varied backgrounds and experience with hospice or end of life care.

It was critical, of course, to interview a number of volunteers as key informants. The three volunteers questioned each had at least five years' experience with Ridge Valley Hospice. Interestingly, they were also caregivers at one time for loved ones who had received hospice care. Such experience was an impetus for their joining a hospice organization and serving patients facing the end of life, and impacted their approach to care for patients. The Volunteer/Bereavement Coordinator was interviewed due to her extensive knowledge and experience, having served in her position for three years after twenty-two years as a nurse with RVH. Her experience as hospice nurse and Volunteer Coordinator gave her a unique perspective concerning volunteers and patients. She also initiated the conversation regarding guidance for volunteers when dealing with feelings of guilt and regret among the patients. The Director of Pastoral Services had been in his position for thirteen years at the time of the interview and worked with a number of patients at the end of life. He also worked closely with Ridge Valley Hospice through a Clinical Pastoral Education program. The Director was a former Roman Catholic priest and was once a member of a Mennonite church. These experiences enabled keen

insight into the various ways of viewing and responding to issues of guilt and regret.

The responses in the interviews offered a variety of thought regarding the role of the volunteer and their relationship to the patient, especially regarding guilt and regret. Other themes emerged that were related or could impact the primary research interest.

Regarding guilt and regret, the volunteers mentioned that patients they visited seldom divulged much concerning these matters, at least directly, though two volunteers related several stories or incidences touching on such issues for patients. Although she was reluctant to delve into such concerns, one volunteer expressed quite clearly the heart of the research, “I think we all have guilt. You can’t get away from it, because we’re human.”

Even though there was a window of opportunity to address guilt or regret on occasion, even in a basic way, the volunteers were reticent. The reluctance to respond was due, at times, to a hesitancy trusting their instincts and intuitions. Several volunteers confessed to “not knowing what to say,” or “where to go with it.” As one volunteer put it, “I’m not the pro.” Usually, though, two of the volunteers would pass on the patient’s spiritual concerns to the Volunteer Coordinator. The third volunteer mentioned several occasions when she asked permission of the patient to contact the volunteer’s local pastor, who she believed could better help the patient with their spiritual struggles. The volunteer did not indicate if she alerted the Volunteer Coordinator or Hospice Chaplain and it was unclear if the issues had to do with guilt and regret.

Even though hesitant at times or even unwilling to move into deeper conversation regarding guilt and regret (or other significant spiritual matters), the volunteers often normalized patient stories and comments in healthy and appropriate ways. None expressed shock or judgment, and would often make comments or share a story indicating they could relate to the patient’s pain or feelings of guilt. The volunteers were also good listeners, attentive to and

deeply engaged with the patient, and desired to offer positive, upbeat presence. As one volunteer shared, the patient and family had enough to deal with and her role was to be encouraging and supportive.

There was much less noticed or said regarding guilt and regret among caregivers, staff or volunteers. Only one volunteer shared that she experienced feelings of guilt at times, but she also expressed healthy ways of dealing with the underlying concerns. Two volunteers spoke of possible ways that family could or did feel a sense of guilt or regret. Nonetheless, it was clear that all of the volunteers were primarily focused on their relationship with the patient, though relationships with some caregivers naturally arose in such intense and intimate circumstances.

The Volunteer/Bereavement Coordinator asserted that she had experienced a significant level of expressed guilt and regret among patients in her twenty-five year tenure with Ridge Valley Hospice. She was also able to name specific examples of guilt and regret expressed by patients and caregivers, indicating that these concerns often resulted from an inability to communicate or be honest about feelings, and fear the loved one who was dying would be upset. She also spoke of times that staff and volunteers had shared such feelings, but again, these examples were far less prevalent than incidences regarding the patient and caregiver. The Volunteer Coordinator dealt with such issues relying on her own intuition, insights and experience, offering affirmation and support. However, she expressed that she was keenly aware of when referral was needed, though she gave no specifics.

The Pastoral Services director at Penn Foundation also dealt with issues of guilt and regret on a regular basis among those facing the end of life, both as a priest and as a chaplain in the pastoral care/CPE field. He offered rich descriptions regarding guilt and regret in terms of possible causes and remedies. The Director echoed the sentiments of the Volunteer Coordinator

regarding a lack of communication among hospice patients and caregivers. He said many are often “afraid that in speaking the truth, or from an authentic self, that their relationship would be jeopardized...so they withhold it, swallow it, bury it, or tuck it away....”

One of the volunteers expressed a desire for education and training that would offer insight into helping patients struggling with guilt or regret. The Volunteer Coordinator also hoped for a workshop or training to assist volunteers and staff. “So many people are walking around with guilt and regret,” she said, believing that appropriate education could help “open avenues of conversation” that could lead to reflection and healing.

Other themes emerged from the interviews that had relevance to this study. Some were consistent with ideas expressed in the literature while a few others were notions the literature did not address.

Friendship was often mentioned as a way to describe the relationship between volunteers and patients, or at least to describe how patients perceived the relationship. Some volunteers also mentioned that friendships developed with caregivers, while one volunteer admitted to a sense of guilt when they could not maintain friendships with family after the death of the patient.

The Volunteer Coordinator indicated that when patients view the volunteer as friend, it often allows for more honest sharing regarding pain, or other matters, like guilt and regret. This sentiment was echoed rather clearly by one of the volunteers: “I think they tell us volunteers more than they tell you people.... The professional may judge them...so they end up spilling more to the volunteer. It gets to be a friendship with the volunteer.” However, another volunteer was more cautious about becoming friends with the patient, which they believed could adversely influence relational dynamics and the volunteer role. Nonetheless, she accepted the idea that patients might consider her a friend, though the volunteer was careful to maintain appropriate

boundaries.

As noted above, *communication* was an important topic that emerged and was consistent with the literature. Lack of communication in relationships, by withholding emotions or information from the person one loves or cares for, was clearly seen as a factor contributing to feelings of guilt and regret. Communication, and the ability to be open to others in healthy and appropriate ways, was seen as critical to the spiritual and emotional health of the patient. Similarly, appropriate avenues for communication among the hospice team members, as well as with patient and caregivers, was also seen to be essential for quality care.

Communication in non-verbal ways was also important in the patient/volunteer relationship, as was a positive attitude. The Volunteer Coordinator felt that “the little things – a smile, a grabbed hand, a thank you for coming, tells me that I have made a connection.” In fact, *making a connection* was mentioned by most interviewees as crucial to the role of the volunteer and the volunteer/patient relationship. Connections were made through a variety of ways, like prayer, conversations about family pictures or special items in view in the house, a therapy dog or simply showing up on a regular basis.

As discussed in the literature, *community* can also have a profound impact when dealing with issues of guilt and regret and related matters. As one respondent articulated, authentic community entails “being known and knowing at a deep level people who care for me and whom I care for.” Even though it is important for volunteers, staff and others involved in the care of the patient to provide a sense of community and belonging for the patient, nurturing community among hospice volunteers was mentioned often, and is seen at Ridge Valley Hospice as crucial to the health of the volunteer and the quality of the relationships and care offered the patient.

Gratitude was a theme expressed in every interview in various ways. Some mentioned a

sense of gratitude for the privilege to share in another's life and to care for those in need. Others spoke of the necessity of developing gratitude or an attitude of thanksgiving as a way to deal with issues of dying, spiritual difficulties and guilt and regret. Affirmation and a positive view of life were also critical to the thankful heart. Gratitude was often mentioned as a source of strength for those involved in hospice and end of life care.

All of the respondents mentioned some aspect of *faith* in their interactions with patients, some touching on forgiveness or some other remedy for guilt or regret. The Director of Pastoral Services mentioned several avenues for forgiveness, speaking most directly about his experiences as a priest (and the sacramental system), as well as the Mennonite tradition where forgiveness and assurance of God's grace is mediated through the community. In either case, he emphasized forgiveness as a "critical step" toward healing as well as the possibility of the volunteer being an agent of hope when the patient struggles with guilt or shame. At least one volunteer expressed the need for caution regarding discussions involving faith, emphasizing that conversations regarding these matters were at the prerogative and initiation of the patient.

The Volunteer Coordinator noted that societal attitudes about expectations influenced the level of guilt felt by patients and caregivers. She believed that a shift from "doing the best you can and being happy with that," to "you must be the best at what you do" was destructive and undermined the ability to forgive and nurture gratitude.

Others did not use explicitly theological language, but saw the need for comfort, affirmation, and listening as critical for the patient's healing. Some assisted the patient, when invited and appropriate, to find meaning in their faith or to recover their religious heritage so they could experience God's grace.

Several interviewees offered examples of spiritual interventions that helped patients and

caregivers deal with guilt and regret while one volunteer prayed with patients and engaged in religious rituals (the rosary) when appropriate, though there was no indication that these interventions touched on patient guilt and regret.

In a follow-up conversation with the Volunteer/Bereavement Coordinator I presented my findings from the interviews. One concern was the interviews appeared to indicate a clear divide among volunteers and staff/professionals regarding the frequency of encounter regarding guilt and regret. The staff (echoing the literature) indicated these issues surfaced on a regular basis among patients, while the volunteers interviewed had few such incidences to report. I also shared the volunteers reluctance to deal with difficult issues (like guilt and regret), a concern to be friend to the patient, and a focus on a positive atmosphere to counter the “negativity” that can be pervasive at the end of life. I also mentioned I noticed among the volunteers a range of attitudes and practices regarding their role.

The Coordinator responded that all the volunteers interviewed had expressed concerns in the past about issues that had connection to guilt and regret. In fact, they and other volunteers were hopeful for a workshop or training to assist such issues. The Coordinator also disclosed that the volunteers interviewed often communicated these issues in various ways. For example, when one volunteer submitted official notes of the visit she always attached, on a separate paper, detailed personal comments in which she spoke about problems or issues that she did not want to include in notes for the patient’s file. Another volunteer, who helped with tasks in the Ridge Valley Hospice office in addition to making visits, would speak directly to the Coordinator about problematic issues when working in the office. The Coordinator related that some of the problems involved issues regarding guilt and regret. The Coordinator and I questioned whether the volunteers recognized the issues they presented as ones that touched on guilt and regret. We

also wondered if better training would help and if so, in what way.

SURVEY FOR RIDGE VALLEY HOSPICE VOLUNTEERS

Using the information from the interviews, coupled with research into survey instruments, a survey was developed to further investigate major themes, especially focusing on guilt, regret and associated issues. There were also questions that addressed possible areas for volunteer training associated with subjects related to guilt/regret, forgiveness and spirituality.

As mentioned in the previous chapter, 90 surveys were sent to active volunteers. 45 surveys were returned for an overall response rate of 50% (45/90). The researcher later discovered through conversation with the Volunteer Coordinator that, of the active volunteers, only 73 provide direct patient care, while 20 offer other services important to RVH. Of the 73 who provide direct care, three are volunteer chaplains. The volunteer chaplains did not receive the survey, which meant 70 volunteers who provided direct care received surveys. Two survey responses were from volunteers who do not provide direct care to patients (as noted on their form) and were excluded. It was implicitly understood that the remaining 43 surveys were from volunteers who provide direct care to patients. Therefore, the effective response rate was 61.4% (43/70). The results were tabulated and are reported in Appendix D.

The survey revealed a number of interesting findings, many in keeping with the comments from the key informant interviews. Data suggest respondents understand and practice the essential aspects of their role as a hospice volunteer, including being a compassionate listener (93.0% most/all of the time), offering an upbeat presence (83.7% most/all of the time), and offering appropriate documentation or verbal report of the visit with the patient, especially when the patient is struggling with some issue or problem (83.3% most or all of the

time/documentation, 51.2% most or all of the time/verbal communication).

Regarding spiritual issues in general, the respondents indicate they discuss God or faith sometimes or most/all of the time (73.8%) while 58.1% engage in a religious or spiritual ritual or practice with the patient sometimes or most/all of the time. This is significant since hospice volunteers are trained to be cautious about entering conversation regarding religion, faith or spirituality during their visits with patients, unless given permission by the patient in some way. One interviewee stated this guideline rather clearly when she shared that volunteers were not supposed to “talk about faith” with the patient unless the patient “opened the door.” However, all of the key informant interviewees’ revealed sufficient examples of times they engaged in religious/faith oriented conversations or rituals. This meant the door was opened quite often or the volunteer inappropriately crossed boundaries. In an area where religious practice is common, and faith conversations can happen easily, the former is most likely. Also, there was no indication from the Volunteer Coordinator that volunteers crossed boundaries by initiating faith-oriented conversations.

There were other questions that revealed a consistency with the key informant interviews. 42.9% of the respondents acknowledged developing a friendship with the patient or family member most or all of the time, while another 33.3% did so at least some of the time. Although the question mentioned family members, the key informant interviews revealed that friendships were formed primarily with the patients. However, friendships did arise at times with family members, though not as frequently or, typically, with the same intensity.

The surveys also confirmed the practice by volunteers to normalize patient stories and struggles by sharing their own personal anecdotes (54.8% sometimes, 28.6% most/all of the time). The volunteers were also sensitive to conversations with patients that focused on gratitude

at least some of the time (58.1%) or most/all of the time (32.6%). Response for both queries bolstered the notion expressed in key informant interviews that volunteers are to provide a positive, upbeat presence, offering the hospice patient a sense of companionship and connection.

On the other hand, it was somewhat surprising, in light of the key informant interviews with volunteers, that 23.8% of survey respondents indicated they sometimes discussed guilt and regret with patients. Although a significant amount of respondents never discussed these issues in their interactions and visits with patients (31.0%), those who had engaged the subject at some point, even if rarely, was 69.1%. Further, there were two questions, numbers four and six, that inquired about concerns that often lead to or underlie feelings of guilt or regret among patients (broken relationships/burden of care). The results having to do with conversations between patient and volunteer about broken relationships were consistent with those regarding guilt and regret. However, 50% of the volunteers who responded indicated they had discussed the burden of care on family members at least sometimes, while 85.7% of respondents had exposure to this issue while visiting patients. This discrepancy merited further discussion in subsequent research.

Questions 21 through 27 were asked to gauge volunteers' perceptions of their own comfort level or need for training regarding concerns related to guilt and regret and related spiritual issues. 78.1% of respondents felt somewhat or very comfortable talking with patients about God and faith (question 23), which was consistent with responses that they actually converse with patients about these matters (question seven, 73.8% sometimes or most/all of the time). However, while 65.9% of volunteers indicate they feel somewhat or very comfortable discussing broken relationships with patients, only 25.6% say they sometimes do, while 74.4% responded they never or rarely speak with patients about these issues (question four). This indicates a possible discrepancy between perception of ability or comfort level and actual

practice.

Another similar inconsistency is found when comparing responses regarding volunteer comfort level discussing forgiveness (57.1% very comfortable, 23.8% somewhat), and the number who actually discuss feelings of guilt and regret with patients (73.9% never or rarely). If guilt and forgiveness are closely related, and adequate exploration of forgiveness will necessarily touch on issues of guilt, then this discrepancy merits further research and a possible need for training.

There were a significant number of respondents (17/43, or 39.5%) who desired training in at least one area mentioned in the survey that focused on patient care (questions 21 through 26). 11 of 43 respondents (25.5%) mentioned a need for training in three or more areas. The greatest need for training of those listed were in the areas of broken relationships (28.8%), communication between family members (26.2%), God and faith (22.0%) and caregiver burnout (22.0%).

The survey also provided volunteers a chance to list their number of years' experience with hospice. Of the 24 who noted their time spent as a volunteer with RVH, 12 had five years experience or more, while 12 had three years or less. It was surprising that a higher percentage of those with more years experience indicated a desire for three or more trainings (5/12, or 41.6% of those with five or more years experience vs. 2/12 or 16.7% for those with three years or less experience). Interestingly, two respondents with less than a year experience desired training in just one or two areas, while feeling confident in most areas listed in questions 21 through 26. The respondent with the most years of experience (15 years) indicated a desire for training in *all* of the areas mentioned.

The survey also provided a chance for comments and there are a few worth mentioning.

First, several respondents mentioned that many interactions volunteers have with hospice patients are limited regarding the possibility for in depth conversation. There are enough patients with advanced dementia, or who receive hospice care a very short period before they die, that significant and meaningful conversation is challenging or impossible.

One respondent suggested using round table discussions as a method for training. They further indicated that all of the topics listed in the survey would be “great conversation starters” for intentional exchange and conversation between volunteers.

As noted in the previous chapter, the results from the survey were compared to the themes and ideas from key informant interviews and presented to the Volunteer Coordinator. It was decided to continue research into the role of volunteers regarding guilt, regret and related spiritual issues. Findings from the interviews and survey were used as a basis for further investigation with a focus group of selected RVH volunteers. In particular, exploration was to focus on *a priori* themes (e.g., guilt and regret, the volunteer role), inconsistencies mentioned in the discussion above, and important topics that emerged from conversation with the volunteer focus group. Further consideration of these issues, especially in light of the findings from the focus group, will be treated later in this chapter and the discussion in Chapter 5.

VOLUNTEER FOCUS GROUP

The focus group members included (names have been changed to protect confidentiality):

John, who worked full-time, but looked to volunteering as way to do for others and to do “something meaningful in his life.” He had been actively volunteering with RVH for a year.

Jan, who also worked full-time. Her decision to join hospice resulted from a deeply touching experience with hospice care given to a family member. Jan had been a volunteer for

two years.

Laurie was unemployed and was looking to do something meaningful in her life. She had previous coursework in death and dying issues and also had very positive experiences with family members receiving hospice care. She had been a volunteer for one year.

Shauna had been a volunteer at RVH for four years. She was retired and had experience in education and educational counseling. She was fascinated with issues regarding death and dying and had a family member enter hospice care while she was a volunteer. Like the others, she found her experience as a volunteer to be very rewarding.

Barbara had a positive experience with hospice care as a teenager, when a family member was dying. Other relatives also took advantage of hospice services at various times in her life. Barbara was retired, enjoyed talking to people and found volunteering to be very worthwhile. Although she was a volunteer for slightly less than a year, Barbara's caseload was heavier than normal.

Paul had been a volunteer for a year and a half. He also worked full-time and was looking for a way to touch others' lives in a meaningful way. He was "craving honesty" and felt as though there had to be "a lot of honesty at the end of life." He also had educational experience regarding death and dying and had been a companion with relatives who were dying, but who did not receive hospice care.

Sharon was also retired and had a personal experience facing the possibility of death. She believed her experience could be used to help others at the end of life. She had also been a close companion of relatives who received hospice care. Sharon had been a volunteer at RVH for a total of eight years. She also felt as though volunteering was "more rewarding than anything she had done. People are so grateful," she added, "but I am the one who is privileged."

Sharon was the only member of the focus group that participated in the key informant interviews.

Brittany had been a volunteer for two years. Her involvement at RVH was due, in part, to a “long history of death.” From early in life she had experienced the death of loved ones and a few friends that deeply impacted her life. With the exception of one relative, all had been on hospice care. *Brittany* had also taken courses touching on death and dying and was discerning a call to work with those facing the end of life.

Although the conversation at the beginning of the first meeting was a bit tentative, the discussion for each focus group session turned out to be lively and engaging. At the end there was disappointment that the focus group meetings had to end, and there was a desire for more opportunities to discuss topics relevant to their volunteer role.

The questions for the sessions were used to initiate and guide the discussion. Some of the original inquiries were excluded or altered depending on the direction of the exchange between group members. Probing questions were asked for clarification, to refocus the conversation, or to push the discussion to a deeper level.

There were a number of *a priori* themes, including guilt and regret, faith and religious ritual as well as a focus on the volunteer role. The group members had a good understanding of the areas and issues that might contribute to feelings of guilt and regret, listing a number of possibilities when asked. There was also a growing awareness during our discussions that patients and families might be carrying unspoken hurts and feelings that could lead to agonizing guilt; or, there was recognition of estrangement in families due to broken relationships. Most group members understood, and some had experienced personally, the debilitating consequences of unresolved guilt.

However, like the volunteers queried for the key informant interviews, the focus group

members had little to share regarding conversations with patients about guilt and regret. Similarly, the few anecdotes mentioned that touched on these concerns indicated a reticence of the volunteer to delve more deeply. For example, Sharon related a story about a patient that was a World War II veteran. He was soon to be deployed when he “broke his leg or something” and was unable to go. He later discovered that the person who went in his place was killed in battle. “He told that story many times,” Sharon said. “He felt something, some responsibility for the other guy’s death, which wasn’t true, but that’s the way he felt.” She also disclosed that the patient spoke with his priest about his feelings, but Sharon had a nagging intuition that the priest’s response to the patient, that “this was God’s plan, not yours,” was not fully accepted or embraced by the veteran. The volunteer listened to the patient’s story, but never responded or asked any follow up questions, unsure of what to say or how best to help him. She did share the story with the RVH Volunteer Coordinator, who Sharon thought, “got somebody to talk to him. You know,” she continued, “he wasn’t asking for forgiveness, but it bothered him.”

Several volunteers, especially those who had two years or less experience, indicated that the patients they visited “seem[ed] to be in a good place” regarding spiritual issues. The volunteers who did have interaction with patients that touched on guilt and regret or some other serious spiritual issue listened well to the patient’s story. Typically, they felt the patients who spoke about these problems, even if they mentioned them repeatedly, simply wanted to express these feelings in the presence of someone who would accept and not judge them. For example, Shauna spoke about her interactions with a patient who revealed how “nasty she had been to her family.... It was a situation where I felt like she had to unload that, so I didn’t have to say anything and I just listened to what she said. *She would go on and on about these things...*” (my emphasis).

Even when it appeared that the patient was in a good place, there were a few comments made by patients that could have some underlying feelings of guilt attached. For example, the volunteers indicated a number of patients, especially those in their late eighties or older, wondered why “God has left me here...why doesn’t He take me.” Several in the group believed this statement could simply mean the patient was ready to go. But, the group also discussed whether it possible that something else was behind the question. They came to recognize that the patient who expressed such uncertainty might be feeling some guilt about being a burden to loved ones and others.

When asked about patients verbalizing a need for forgiveness the group members replied that none of the patients they visited had ever expressed that need, at least directly. The group discussed specific instances already mentioned that could have been opportunities to address forgiveness, but there was a reluctance to make such connections. In fact, in contradiction to the survey responses, the group members expressed a sense of discomfort with addressing a patient’s concerns regarding forgiveness head on. As Sharon put it, “for them to use the word, to say ‘I want forgiveness,’ that would be pretty heavy.”

Initially, the group indicated their response would be to contact the Volunteer Coordinator if such an issue arose, and that dealing with deep issues like these were not “their place.” Rather, some mentioned that engaging in conversations about forgiveness was more the chaplain’s role. Further conversation, though, revealed openness to aiding the patient’s struggles, and that part of the difficulty was having the appropriate language or knowing best how to address these concerns. The discussion seemed to generate some deeper interest, for after conversation about another subject, several in the group returned to aspects of forgiveness and an acknowledgement that we all need to forgive and be forgiven, but it is indeed a difficult thing to

do.

Unlike the key informant interviews and responses in the survey, there was little response when asked *directly* about discussions or practices with patients concerning issues of faith, religion and religious ritual. However, throughout other sharing during the three focus group sessions, the volunteers mentioned a variety of faith issues or religious ritual they had engaged in with patients. Religious ritual or practices included different prayer experiences, reading the Psalms and other scripture or sharing a devotional, singing hymns, and going to church with the patient (at a nursing home).

Regarding faith discussions, group members mentioned conversations with patients about salvation, what it means to be a believer, visits from angels, fear of dying or the dying process, readiness to meet God and eternity, questions about God's inaction regarding a patient's impending death, dealing with a patient who wondered what he should believe as he neared death, and issues that touched on guilt and regret. The group members said they had experienced patients who were questioning and struggling regarding faith, as well as those whose faith was "figured out" or who were assured of their relationship with God.

Several group members echoed the key informant interviewees regarding conversations about religious issues. They took care to stay away from conversations about religion or faith issues unless initiated by the patient. If the conversations did arise, the volunteers were cautious about interjecting their own beliefs unless asked. One group member spoke of her concern regarding deeper exchanges about faith issues for fear of doing harm to the patient, a feeling other group members recognized and acknowledged.

As mentioned earlier, the group members were more than willing to refer a patient, through the volunteer coordinator, to someone with more expertise regarding spiritual issues.

However, even when seeing a chaplain, or having other spiritual support, there were some patients that still wanted to share issues and concerns with the volunteer. For example, Barbara spoke several times in different focus group meetings about a patient who was trying to sort out his beliefs and faith. He was seeing at least two other religious professionals (chaplain, priest) that he connected with and was helpful. However, the patient still insisted on addressing his concerns with Barbara and, as she shared, “it seemed like I helped him to clarify.”

Critical to the discussions above, as well as this project, was the volunteer’s perception of his or her role in the care of the patient. The volunteers expressed a strong sense of the fundamental aspects of their role as a volunteer. For example, all of the group members articulated their responsibility to be a “listening ear,” and to be a compassionate, accepting/non-judgmental and upbeat presence. Paul put it well, “I am there to give them a little smile, a little companionship, a little comfort....I just think that whatever time is left for them should be as comfortable as possible. That’s how [the RVH Volunteer Coordinator] trained us.” As mentioned earlier, the group members were also aware of the need to communicate issues verbally, or through submitting required hospice notes of the visit. Most indicated that they communicated thorny, complicated or difficult issues verbally rather than by way of notes.

There were other important ways the volunteers described their role. The volunteers articulated that those who were dying needed to know someone was “making that journey with them,” and that it was critical for the volunteer to make a connection with the patient. If not making a connection, or floundering in terms of what to do, the volunteers felt as though they were failing at a primary task. Of course, connection could happen on a variety of levels and in various ways. It could happen by helping with chores, holding a patient’s hand, listening to stories about family or through praying and reading scripture. Several volunteers indicated, and

the others agreed, that patient needs would often help them to discover their role. As one participant expressed, “it is the patient that teaches you how [to help as a volunteer].”

One of the challenges of defining and discovering their role was struggle with authority or knowing what to do in particular situations, especially times when the patient was dealing with spiritual or existential concerns. When the patient brought up spiritual struggles, the volunteers expressed they were often at a loss how to respond, primarily due to lack of training or knowledge, fear of harm to the patient, or their own discomfort with such issues. However, as with the volunteers in the key informant interviews, several in the group often normalized patient stories and comments in healthy and appropriate ways.

What also influenced group member’s thoughts about being a volunteer were their own experiences with loved ones or friends who received hospice care. Those occurrences shaped their desire to volunteer with hospice and gave them some insight regarding how to treat and interact with patients. They were also motivated to volunteer by a deep desire to help others and touch their lives, to “give something back,” and to find meaning in life. Some were looking for spiritual depth, honesty about life, or even personal fulfillment. However, even when the motivation was personal, the volunteers quickly gained a deeper perspective. As Jan admitted, “what I had thought initially was that I was there for myself, to feel good...but I realized I am there for them. I have to love them in whatever way I can....”

Closely connected to understanding the role of the volunteer is having some grasp of the fundamental needs of the patient. In concert with the literature, the volunteers understood that dying could be a very lonely and fearful process. The focus group also indicated that patients had expressed feelings and stories to the volunteer that they were unable to share with loved ones. Further, there was a perception that some patients needed a trusted companion, or friend,

who would be a consistent presence in their lives, someone willing to be open to talk about anything.

However, not every patient has such needs, or there are times when the connection between patient and volunteer remains on the surface or simply deals with routine or simple concerns. The volunteers also emphasized that a number of patients they visit have medical conditions, like dementia, that limit conversation or connection. Further, the volunteers mentioned they are sometimes assigned to patients who are unresponsive and very close to death. Brittany echoed the sentiment of all the volunteers when she remarked, “it’s so sad when they sign up so late and can’t take advantage of the services” provided by hospice and the volunteers.

There were several important emerging themes from the key informant interviews that were further explored in the focus groups sessions. One of the most interesting issues, and one not covered in the literature, was *friendship*, or the nature of the relationship between patient and volunteer. As mentioned above, every group member looked for ways to make a connection with patients through various means, and these interactions would often move beyond a surface level. As Paul remarked about one patient, “we’re just basically two old guys swapping stories.”

As the group members discussed and touched on their relationships with the patients throughout the focus group meetings, it was interesting to observe the volunteers grappling with and describing the various levels of friendship that could or did evolve. When answering a question about this subject, John gave voice to a more basic level of friendship: “that’s what it’s all about, opening up to people, having a smile, just saying hello, just a few words, it doesn’t have to be a whole lot – that’s what friendship is all about.”

In a subsequent focus group meeting, Cheryl, who had been a volunteer for a year, took a step further in reflection on the patient/volunteer relationship: “when patients think of us as a

friend...they don't feel they have to win us over, we're just there for them, so they are willing to say whatever knowing that...it's probably not going to be a deep, deep relationship."

Several in the group believed that friendship was central to their role as a volunteer, at least with patients who were aware and able to share in this way. Barbara was rather animated in her response to a question regarding the advantage of being friends with a patient, and that the relationship could indeed have a depth greater than Cheryl suggested:

I think it makes them more comfortable, to be able to open up to somebody. Or maybe they can't tell their kids or their spouse how they are feeling (group affirmation), especially if it is something with guilt or with whatever. I think, when you are a friend with them, and that's what I consider myself as a hospice person, a friend...[it allows] them to open up and say whatever they need to say and get whatever they need to get off their chest. I'm there to listen and that's what I enjoy doing....

It was evident that the connections other volunteers had with a number of patients did indeed move to a deeper level and that the dynamics of the volunteer/patient relationship changed in some significant way. Shauna spoke of a particular patient and visible signs of such a change:

I look forward to seeing all of [the patients], but there's one in particular that I've really grown close to.... I don't know when things started to change for her, but a month ago or so, she said, "wait a minute I have to give you a hug," and now it's a hug and a kiss. I don't know if it's because we've clicked or because her family, especially her daughter, is not close by. I know it will be difficult for me when something happens.

Although other group members did not have so clear a sign that relationships with some patients moved to a new level, most described or recognized changing dynamics and described the relationship in terms of “growing close,” or using directly the term friendship to name the deepening connection. Such relationships did not evolve within days or weeks, but took time. Sharon expressed the sentiments of most group members when she mentioned that, “the longer you have a patient, the more you become a friend and they do share with you. It’s a part of your life.... they communicate their humanness and their appreciation that you’re there.”

It was not a surprise that deeper relationships developed the longer a volunteer was able to spend with a patient, but the depth of some of those relationships were rather profound and led to intense grief and mourning when the patient died. Jan described one such moment when she learned, after returning from vacation, that a patient she had grown close to was actively dying. At the behest of the Volunteer Coordinator, Jan decided to visit, though she was unsure she could deal with it emotionally. She did go, and “sob[bed] all the way to the nursing home.” Jan shared that she was surprised by her reaction, but was happy she was able to say her goodbyes.

There was also recognition that there was a need for friendship, or some relationship of deep trust, for good and productive conversation and sharing to take place regarding spiritual issues, especially those that touched on guilt, regret and forgiveness. Further, all of the group members experienced, or understood to varying degrees, the sacredness of the journey with the patient and the potential for profound relationship. Sharon put it rather succinctly, “I think dying is a lonely process, so having a friend is a real gift...so if you can get that connection, man that’s the best.”

Closely connected to the discussion about the patient/volunteer relationship are issues regarding communication. Some of these issues have been mentioned already (e.g., working

with patients with dementia) and do not need cited again. The group also wrestled with issues of honesty and “being real” when dealing with patients, times when it was prudent to limit their response, especially when being totally forthcoming could derail conversation or even undermine relationship. A number of these examples involved religious belief. For example, Paul related a time when the patient asked if he was a believer. Knowing that this could be a loaded question, and that “being a believer” had many connotations, Paul simply replied “yes.” Knowing when to show restraint opened the door for Paul and the patient to become immersed in a deeper and mutually instructive conversation. It also led to a more profound trust and relationship.

Finally, the last subject discussed at length or mentioned at various times in the focus group meetings were issues regarding desired training or education. Some were concerned about what to do when they could not make a connection, especially with those who were less responsive or dementia patients. At one point, after Brittany shared her experience with estranged families in her work with a funeral home, conversation quickly focused on the need to deal effectively with built up anger or bitterness, as well as broken family relationships. Sharon asked me pointedly if I had a “recommended safety valve” for such issues or problems. The affirmations and response to her statement indicated a desire of most in the group to have some training or knowledge of such issues and how best to help.

Much of the discussion regarding training and education had to do with how to handle conversations about guilt, regret, forgiveness, belief, and spiritual issues. As Sharon asserted, “we all feel like we are not trained in this...it’s complicated. It would be helpful for us to get general info so that we could understand.” Some suggested various ways this information could be communicated. One idea was to develop a guide about what to say and not say regarding specific concerns or issues – “a list do’s and don’ts, or possible gray areas” when discussing

critical problems like guilt and regret, or patient struggles over what to believe. Another similar idea was a handbook that listed basic beliefs and rituals for different religious groups and faith communities. Some also mentioned becoming more familiar with the life review questionnaire already available for use.

In addition to written material, some suggested workshops or some other kind of training, including teaching through methods like role-play, or including seasoned volunteers that could share their experiences and be involved in a question and answer time. All of the volunteers deeply appreciated and learned much from the focus group meetings and suggested further meetings in the same vein, with a topic to be discussed over two or three sessions.

In short, the group was energized by our experience and hungered for more opportunities to explore their role as a volunteer, so they could better assist and serve the patients in their care. The responses from the focus group, coupled with the key informant interviews and survey, also provided rich descriptions and information to address the volunteer role with the patient, especially regarding guilt, regret and forgiveness. The data from the three methods of research also reached a saturation point, with no new information emerging from the focus group research.

DATA TRIANGULATION – EMERGING THEMES

The data offered consistent results in a variety of critical areas regarding volunteer/patient interaction, while inconsistencies were also evident. Each research method revealed volunteers were confident in the basic aspects of their role and interaction with the patient, listening attentively to conversations and stories, offering a non-judgmental and encouraging presence. Volunteers were also respectful of boundaries, and often provided personal anecdotes when

appropriate to normalize patient struggles and questions. In short, the volunteers were genuine and caring in their relationships with the patient, to such a degree that a number of patients often considered the volunteer a friend or trusted companion. Of course, not every volunteer/patient relationship was regarded in such a way, but the potential for a trusting and friendly rapport was often present, especially if there was adequate time and an ability to communicate effectively between patient and volunteer. The volunteers were also hopeful for training in areas that might assist with handling issues like guilt and regret, forgiveness, or other spiritual or difficult issues. Even though the survey did not indicate as strong a desire as occurred with the key informant interviews and the focus group, it was evident from the data overall that volunteers would benefit from more training regarding the issues critical to this research. Better training, at the least, would help with communicating problems and concerns more effectively to the volunteer coordinator, chaplain, or other spiritual counselor.

Religious and spiritual issues: Guilt, regret and forgiveness. The research also indicated patients and volunteers engaged in conversation that touched on existential, religious and spiritual matters. The volunteers were careful regarding such conversations, being sure to enter discussions only when patient-initiated. However, if the invitation was present, most volunteers felt comfortable talking about matters of faith and God, as well as working to find ways of connection through approaches like inspirational stories, prayer, singing hymns and listening carefully to patient anecdotes regarding aspects of faith and spirituality.

On the other hand, the volunteers who were key informants or part of the focus group indicated a reticence to delve too deeply regarding religious and spiritual matters, especially pertaining to the focus of the research – namely, guilt, regret and related spiritual concerns, like

forgiveness. Their reluctance often hinged on issues regarding lack of knowledge/training, authority (“I’m not the expert,” “that’s a matter for the chaplain”), crossing boundaries, and a feeling they might do harm to the patient by saying or doing the wrong thing. In addition, even when volunteers described conversations with patients that touched on potential issues of guilt and regret (or a need for forgiveness), there was a lack of awareness, or ability to identify, that such issues could be imbedded in the comments, stories and concerns of the patient.

The survey results also indicated areas of possible discrepancy and uncertainty, especially regarding *a priori* themes. The survey revealed the majority of respondents were somewhat or very comfortable discussing topics like communication issues (69.1%), broken relationships (65.9%), faith (78.1%) and forgiveness (80.9%) with patients. However, in practice, only a quarter of the volunteers surveyed engaged in conversations about broken relationships or guilt and regret. In fact, nearly a third of respondents indicated they *never* spoke about such issues with the patient (broken relationships, 37.2%; guilt and regret, 31%). The disparity between the comfort level speaking about forgiveness and the responses regarding guilt and regret are especially worth noting. Such a gap in comfort and actual practice could result from a number of factors. For example, it’s feasible that most patients are secure and comfortable regarding their spiritual wellbeing and so conversations with the volunteer simply express that assurance. It might also be a result of the volunteer’s orientation toward being a positive and upbeat presence. In this case, the volunteer may be quick to offer comfort by assuring the patient they are forgiven and loved by God.

However, the discrepancy could indicate disconnect between perceived ability and confidence negotiating such discussions and the skill and insight required to speak about issues of guilt, regret and forgiveness. Or, it may be the case the volunteer lacks sufficient ability and

practice noticing issues of guilt that may arise (as noted above), or overlooks the connection between guilt and forgiveness. When coupled with the focus group's feedback concerning guilt and regret, and especially forgiveness, a picture emerges of volunteers unsure of their role when encountering deeper and critical spiritual issues that arise for the patient.

Friendship. One of the interesting emerging themes from the key informant interviews, and explored through the survey and focus groups, had to do with the volunteer/patient relationship. Namely, as reported by volunteers and the Volunteer Coordinator, a friendship often developed between patients and volunteers. In some cases, the volunteer felt as though being friend, or acting as friend, was critical to their care of the patient. On other occasions the patient considered the volunteer their friend, even expressing this sentiment to the volunteer and in a few instances to the Volunteer Coordinator. What also emerged was the impression that such a relationship allowed for more open and honest conversation between volunteer and patient regarding difficult issues or confidences. In fact, volunteers, and the Volunteer Coordinator, believed patients occasionally revealed critical matters to the volunteer that were not shared with family members or professional staff. One volunteer insinuated the patient, in general, expressed a greater trust for the volunteer over professional staff. Although most volunteers from the key informants and focus group did not share this view, there was definitely a feeling that a high level of trust, akin to what exists between friends, characterized a number of patient/volunteer relationships.

However, using Pearson's correlation, which measures the correlation between two variables (e.g., develop a friendship/discuss feelings of guilt and regret), the data from the survey suggests a different picture than just described. The analysis indicates a weak or insignificant

link between developing a friendship with the patient (question no. 11) and discussing matters that touch on guilt and regret (questions 4, 5 and 6).

The raw data from the survey further shows those who develop friendships with the patient most or all of the time (18 respondents) discuss these critical issues most or all of the time, or sometimes with the patient, at a fairly low rate (guilt and regret: 2/18 or 11.1%; broken relationships: 4/18 or 22.2%; burden of care: 6/18 or 33.3%). For those volunteers who develop a friendship sometimes, rarely or never (24 respondents), the same comparisons indicate, oddly, higher rates of engagement overall regarding these issues (guilt and regret: 9/23 or 39.1%; broken relationships: 7/24 or 29.2%; burden of care: 15/24 or 62.5%).

Although a relationship perceived as friendship may indeed occur between patient and volunteer, the interview, survey and focus group findings indicate this bond has little affect on the ability to discuss difficult matters, especially regarding guilt, regret and forgiveness. Of course, discussing difficult subjects is a risky endeavor and may be avoided due to a perceived fear that the friendship would falter, fail to provide comfort for the patient, or prevent “making a connection.” Or, again, it may be that a lack of knowledge or training among the volunteers inhibits the possibility for fruitful conversation about difficult subjects, even with patients who need to share problematic issues or experiences with someone they trust.

These findings lead to several possible outcomes: (1) the volunteers should not deal at all with issues regarding guilt, regret/forgiveness; (2) the volunteers should be better trained in order to recognize such issues more readily, so appropriate and more helpful information can be passed on to the volunteer coordinator, chaplain or other spiritual counselor; (3) the volunteers should be trained to recognize and, if comfortable doing so, gently explore such issues with the patient. Such engagement would allow the volunteer a chance to be a collaborative participant with those

that aid the patient in dealing with critical spiritual issues like guilt, regret and forgiveness.

Deciding the appropriate direction will also involve addressing the nature of the volunteer/patient relationship, particularly the issue of friendship. Because the research suggests that the desire of the volunteer to be friend to the patient may inhibit substantive conversation, the character of the relationship is important to consider, especially as it relates to desired outcomes by RVH and practices of the volunteer.

Since the patient may not want to speak with a spiritual counselor, or may feel uncomfortable speaking with a chaplain or clergyperson, the volunteer could play a critical role in the patient's desire to explore spiritual matters and healing. The research and literature have shown patients do speak of such matters on occasion with the volunteer, and that the patient and volunteer can develop a relationship of trust necessary for substantial conversations. It is the contention of this author that the research also suggests the role of the volunteer should be expanded to include a broader knowledge of, and comfort with, addressing spiritual issues with the patient. If this is the case, then it is vital that a qualified chaplain, spiritual specialist, or counseling professional provide training for volunteers.

Chapter V

The Role of the Volunteer: Responding to the Opportune Time

THE VOLUNTEER ROLE: PAUL'S STORY

During the first focus group session Paul offered a profound and meaningful story that set the tone for subsequent discussions and provided vivid imagery that exemplified the volunteer role. When he was in his late teens, around seventeen, Paul was walking along a Brooklyn street, near his church, on a cold, dreary Sunday in March. “You have to imagine the landscape a little bit,” he said. “You had sidewalks and then apartments that came right up to the sidewalks. And so the windows were right there” by the sidewalk. As he was walking, Paul noticed that a window across the street was open, which was unusual in the cold weather. Being curious, he crossed the street and glanced in. He noticed a woman slumped in a chair near the window with another woman standing beside her rubbing her arm. The woman standing called out to him, “Please stay with her, she’s not breathing, I’m going to get help.” So Paul reached through the open window to hold the woman’s hand. He realized that she *was* breathing, but very slowly, shallowly, and labored. A few times he gently smacked her hand to revive her when it seemed she stopped breathing. Just before help arrived, the woman’s body slumped and Paul believed she died in that moment. A few minutes later, the companion and a nurse arrived, as did a police officer that told Paul to “move along.” Paul reflected, “this woman died in my presence, though she never saw me. She had no family there. I crossed into her life just at the last minute. Our lives intertwined.... I was standing with her, holding her hand *through the window*. I was literally passing by...” (RVH Volunteers 25 March 2014).

For Paul, now in his early sixties, this was an incredibly meaningful experience that affected his life and even his desire to become a part of hospice. It was an opportune moment, a

time in which a dying woman needed his presence and a touch of the hand, someone who would be a momentary companion as she transitioned from one life to another. It was over in what seemed an instant, but Paul felt as though their lives had come together for a purpose he felt privileged to share.

These and other rich images that emerged in Paul's story shed light on critical aspects of the volunteer role and the volunteer/patient relationship. Of course, the account illustrates the primary role of the hospice volunteer - someone willing to offer the ministry of presence and care at just the moment of need. Even when the volunteer and hospice patient might share only a few hours, or days, or a week, their lives become "intertwined," as Paul described, often in silent, yet profound and mysterious ways.

Similarly, the volunteer is "passing by" at "just the last minute" of a person's life when they attend to the needs of the hospice patient. Whether the volunteer is with the patient for a short time, or for extended periods of months or even a year or more, they have related with the patient for a relatively brief moment in the hospice patient's life. However, in each instance, the experience can be deep and meaningful, especially if a trusting relationship develops between patient and volunteer.

However, the story also hints that a team approach is helpful, and possibly necessary, for sufficient care for the patient. In the narrative, the caretakers were only able to provide comfort and presence in the last moment of life. For those in hospice care, patients are often in need of those who provide comfort, presence and desired expertise to handle the various aspects of the dying person's needs for days or months or years. With regard to spiritual concerns, the expert may be a highly qualified or board certified chaplain who oversees or provides spiritual care. Such care may also include connecting the patient with trusted clergy or spiritual advisor. Even

so, the need for the spiritual expert does not preclude the volunteer (or others, like hospice staff), from gaining a deeper awareness of spiritual distress or issues that may arise for the patient. Indeed, there may be times when the volunteer may be the only trusted person to hear a spiritual concern, or possibly the first to notice and report a patient's feelings of guilt, or a need for forgiveness.

Paul's description of reaching "through the window" was an incredible visual reminder of the opportunities that may arise between volunteer and patient, occasions that give entry to experiences and relationships that allow for connection, comfort and healing. These moments are often unplanned, perhaps even happenstance, but they are nonetheless opportunities to accompany the dying person in a variety of ways, often deepening an important relationship for the patient as they face death. As with Paul that day nearly fifty years ago, the relationship that develops, whether brief or lengthy, should be treated with care. The point of the relationship is not to save the patient, or do more than is possible to do, but to be attentive and offer the best care possible in light of the particular volunteer's gifts and abilities.

Offering the best care possible is the concern of this project, with an eye to developing the skills of volunteers with regard to spiritual care, especially regarding guilt, regret and forgiveness. As the literature and research demonstrate, there are times when volunteer may be asked to "reach through the window" or take advantage of the opportune time, when a patient reveals a concern or shares a story that potentially exposes a deeper need.

It is evident from the interviews, survey and focus group that deeper relationships can and do develop between the volunteer and some patients. However, the data also suggests that these relationships do not erase the discomfort volunteers may have discussing particular issues, especially ones with spiritual import. The interview and focus group responses also indicate

some conversations could have taken a different turn had the volunteers been trained, or were comfortable with the issues that arose. Sharon's interaction with the WWII veteran is a good example. Her intuition that there was a question or issue underneath his story was certainly perceptive. Yet, because Sharon was unsure what to do or say, and was somewhat uncomfortable broaching potentially painful and complicated feelings, she rightly passed along the concern to the Volunteer Coordinator. Even so, there was a desire by Sharon to know what to do in this instance, providing a chance for the patient to consider and reflect on hidden thoughts or feelings. Perhaps there were ways to engage the patient without causing harm that would allow him or her to say more, thus providing valuable information for others who might provide spiritual care. Maybe a well chosen question or statement by Sharon could help the patient to discover if there were underlying pangs of guilt, or if his telling (and retelling) of the story was fundamentally a desire to talk about meaning and life's purpose. Whatever the case, could appropriate training and practice allow her to become a critical participant in addressing the patient's spiritual discomfort or search for meaning?

The essence and implication of this example is that volunteers often find themselves at "the open window" with an opportunity to engage the patient in more significant exchanges that address underlying spiritual concerns. As with Sharon's case, it is not an opportunity that volunteers invite or look for, but is one that often arises due to a level of trust that had developed between volunteer and the patient. Sharon is not alone in her desire to be more helpful, or to gain insight into issues that might be passed along and addressed by a chaplain or spiritual advisor. Although the wish to engage in such conversations is not a hope for all volunteers, there are those who seek knowledge and training, especially regarding issues of spirituality.

Current Practices at Ridge Valley Hospice regarding training and delivery of spiritual care. At Ridge Valley Hospice the volunteers are respected members of the care team. They receive training that is commensurate with that suggested by the National Hospice and Palliative Care Organization (NHPCO) (see “Regulatory Resources for Volunteer Managers”). RVH volunteers are required to attend seven training sessions, about three hours each, before they can begin visiting patients. The sessions at RVH are listed as follows: (1) Philosophy and mission of hospice, the role of the volunteer, confidentiality; (2) Terminal diagnosis; (3) Comfort measures and pain management; (4) Communication and boundaries; (5) Safety; (6) Bereavement, death and dying; (7) Spirituality and hospice (Volunteer Coordinator 17 June 2014).

Although there is instruction covering spirituality, as well as attention given to related subjects like communication and confidentiality, the training in these areas is limited. Consequently, the sessions do not adequately prepare the volunteer to engage significant or complicated issues like guilt, regret and forgiveness with the patient, on even a basic level. At RVH the volunteer is not expected to offer spiritual care, though the research data suggests they often encounter spiritual issues and struggles among some of the patients they serve, and some of the issues are significant. They also tend to some spiritual needs in the form of prayers, reading devotionals and other ways mentioned in the results.

The Volunteer Coordinator was very aware of the need for better training and improvement in the way spiritual care was provided for the patient at RVH, as well as at other hospices facilities with which she was familiar. According to her, those who regularly dealt with spiritual issues at RVH, besides the chaplain, were the nurses and social workers. But, the latter two groups are not trained with any depth either, or in a way adequate to handle important spiritual concerns. The chaplain at RVH, though very competent, is not board certified. Further,

as the Coordinator admitted, it was not possible for the chaplain to handle the census and the entire spiritual needs of the patients. In light of these circumstances at RVH regarding spiritual care, the Coordinator expressed hope that volunteers (and staff) could receive more in depth training regarding spiritual concerns. She believed such instruction could facilitate more awareness of the pertinent issues, better support of patients in their struggles and concerns, and develop greater competence making referrals and providing helpful information to the chaplain or other spiritual caregivers. She was also interested in developing training that would allow for deeper engagement of volunteers with patients regarding issues like guilt and forgiveness, and resonated with the need for especially trained “spiritual care volunteers” (Volunteer Coordinator 5 July 2013, 17 June 2014).

THE VOLUNTEER ROLE: BECOMING A SPIRITUAL CARE GENERALIST

One of the emergent paradigms in literature in the past decade regarding the spiritual care of patients is the generalist/specialist model (Handzo and Koenig; Robinson et al.). This model reflects a needs-based approach to health care (Rumbold) and distinguishes the responsibilities and practices of the spiritual care generalist and specialist. This model also supposes a focus on holistic health for the patient and a collaborative approach among the health care team providing patient care (Rumbold; Handzo and Koenig; Robinson, Thiel and Meyer).

In hospice and palliative care settings (and health care in general), the delivery of care does indeed focus on detailed assessment of patient needs, holistic health and collaborative care. In such a setting, the chaplain is the spiritual care specialist, and whether board certified or not, is “expected to have a functional knowledge of a range of [religious/spiritual] traditions and also to demonstrate the skills to explore sympathetically each individual’s process of meaning-making”

(Rumbold 257). As specialist, the chaplain often *oversees* spiritual care, and is typically responsible for making a detailed spiritual assessment, developing a spiritual care plan, connecting patients with appropriate spiritual resources and receiving referrals for patients requiring the particular skills, knowledge and training of the chaplain to handle challenging spiritual issues (Rumbold; Puchalski et al.; Handzo and Koenig; Robinson et al.; Mann).

Although a specialist for spiritual care, the chaplain is also (or can be) trained to be a generalist regarding other aspects of patient care. For example, the chaplain may be asked to assess the level of physical pain the patient is experiencing during a visit.

Similarly, other members of the care team are needed to be spiritual care generalists. As Handzo and Koenig point out “every professional caregiver, while [they] each have a specialty on the healthcare team, needs to have an awareness and concern for the whole person – physical, emotional, and spiritual” (1195). This awareness not only allows each person on the team to address their particular specialty in a more holistic way, it also allows for better communication with spiritual care specialists overseeing a patient's care. It also potentially enhances the level of spiritual care the patient receives (Handzo and Koenig; Rumbold).

There are a number of particular tasks and responsibilities that can be identified for the generalist. On a basic level, the generalist should be able to recognize, screen and properly document spiritual concerns or distress and know when to refer. Robinson, et al., provide helpful insight regarding the “roles and tasks of the spiritual care generalist and specialist.... suggested sample assessment questions for the generalist.... [and] when a spiritual generalist should consult a chaplain” (726-727). For example, while the generalist should be able to “notice signs of spiritual distress,” the specialist “*identifies and explores* issues of spiritual distress, worry, suffering and guilt,” as well as “identify spiritual strengths, hopes, and

relationships of trust” (Robinson et al. 726 my emphasis). However, in some cases, the generalist may need to be prepared to navigate immediate spiritual concerns that arise in the absence of a chaplain, or when the patient refuses one (Handzo and Koenig).

Borrowing from previous work, Rumbold identifies four levels of need regarding the spiritual care of patients and indicates competency markers needed to provide such care. In his scheme, level one involves “care needed by all,” and requires “basic skills of awareness, relationships and communication,” and the ability to distinguish between religious and spiritual concerns. On this level, practitioners are able to be “alert to spiritual issues rather than enquiring about them” and are able to refer to appropriate members of the interdisciplinary team (259). This level describes, to some degree, many of the volunteers at Ridge Valley Hospice, though some volunteers may fail to notice deeper spiritual concerns imbedded in statements or stories.

Level two is identified as “care needed by many: person-centered care sensitive to the spiritual domain.” Those who provide care at this level must be competent to better identify spiritual and religious needs as well as possible responses to these issues. The screening process in this case is “more likely to include direct enquiry about spiritual concerns” (ibid. 260).

Level three involves “care needed by some: care that addresses spiritual and religious issues,” and involves the ability to make a spiritual assessment and develop a plan of care to address the religious and spiritual needs of the patient. This level also involves the sensitivity and skill to properly discern and record personal patient information (ibid.). Although this level is best managed by the chaplain, or a highly qualified spiritual care specialist, there are some on the team that can, with proper training, conduct a spiritual assessment and work with the chaplain on a plan of care.

Finally, level four concerns “care for the few: care for complex spiritual needs.” Those

competent at this level should have the ability to journey with the patient through various complex spiritual needs, and be able to help the patient as they face death and end of life issues. The practitioner at this level is also able to connect the patient with appropriate external resources or persons, as well as provide training for health care providers in the other three levels (ibid.). Board certified, or highly trained chaplains fit this category.

The scheme provided by Rumbold is quite helpful in distinguishing the spiritual care generalist and specialist as well as the competencies that typify health care providers at each level. In this scheme, levels one and two describe well the characteristics of the generalist's role, while the specialists occupy levels three and four, though the lines may sometimes blur in practice. Whatever the understood tasks and responsibilities might be, researchers in palliative care and other health care fields advocate specific and focused training for the specialist and generalist. The literature suggests the specialist be a board certified, clinically (CPE) trained chaplain or pastoral counselor, who typically has received advanced theological training (Puchalski et al.; Robinson et al.). For generalists, training can range from in-services and workshops to Clinical Pastoral Education (CPE) inspired programs for clinicians that are more rigorous and in-depth (Puchalski et al.; Robinson, Thiel and Meyer).

In most of the literature that addresses these matters, spiritual care generalists are typically other clinicians on the interdisciplinary team (e.g., physicians, nurses and social workers). As discussed earlier, it is important, perhaps critical, to include volunteers as integral to the spiritual care of patients. In fact, Rumbold's presentation regarding the spiritual needs and care of the patient explicitly identifies staff *and volunteers* as those who offer care, listing volunteers as possible practitioners in all four levels (259-262). Although one may assume that level four may include professional clergy or other counselors specifically trained as hospice

volunteers, it is implied that all volunteers can provide spiritual care on various levels as long as they are adequately trained and supervised.

The hospice volunteer, then, with appropriate training, could be a very valuable member of the interdisciplinary team as a spiritual care generalist. Rumbold even suggests that “a needs-based model envisages the bulk of spiritual care being provided by health care staff and volunteers who have received basic skills training.... [and that] chaplains responsibilities will shift from direct service toward training, supporting and mentoring other members of the spiritual care team” (262). Further, as argued earlier, volunteers frequently have a consistent presence with the patient, sometimes developing a trusting relationship with them. This persistent contact and level of trust often allows the volunteer to experience opportune moments in which stories or experiences may be shared that touch on deeper spiritual issues. If the volunteer is adequately trained, these opportune moments could reveal important information and feelings that might lead to profound healing if the issues and information disclosed are handled appropriately and with sensitive care. However, the data suggests that some of these opportune moments are unrecognized or pass by due to uncertainty and/or lack of knowledge or training on the part of the volunteer.

In light of the literature, research, and the needs of Ridge Valley Hospice (and perhaps other hospice organizations as well), training of volunteers as spiritual care generalists could be a critical piece for the spiritual care of patients. If this is the case, it is prudent to re-imagine current training needs for the volunteer with a view to enhancing spiritual care for patients, especially regarding critical issues like guilt, regret and forgiveness. Therefore, some attention will be given to this endeavor, describing what could be included in such education and training.

VOLUNTEER “APPRENTICESHIP”

Training for the hospice volunteer has been given little attention in research and has few guidelines besides those provided through the NHPCO. Although this is limiting for those attempting to standardize instruction, it offers a bit of freedom to responsibly envisage new possibilities, especially regarding spiritual care for the patient. Although there are various ways to approach this imaginative task, there is one scheme suggested by the Carnegie Foundation for the Advancement of Teaching that is helpful, especially for discerning what training may be needed for the hospice volunteer to become a spiritual generalist or spiritual care volunteer.

In 2006 the Carnegie Foundation published their first volume in a comparative study that focused on preparation of professionals. The study was designed to examine and evaluate how particular professions - namely physicians, engineers, lawyers, nurses, academics and clergy – are educated for their work in the world, and to discern what is common and distinctive among educational approaches for the various professions. In their first volume, *Educating Clergy: Teaching Practices and Pastoral Imagination*, the authors suggest that education in each of the professions have a historical basis in an apprenticeship model. In fact, they noted that there were three apprenticeships critical for training in a particular professional life: “cognitive, practical and normative” (Foster et al. 5). In short, the authors maintain that education in these professions are typified by apprenticeships that focus on what a practitioner needs to know; what skills they need to possess to do their work; and what kind of identity they need to have, or what kind of person do they need to be to practice their vocation (Foster et al.; Mellott).

Of course, being a hospice volunteer is certainly not a profession and does not demand the educational rigor expected for occupations like those mentioned in the Carnegie study. However, this author suggests it is a position that requires dedication to acquiring (or having)

particular knowledge and skills, and should also include formation regarding identity, or the kind of person one needs to be, to best serve as a volunteer. In fact, using the language of the Carnegie authors regarding clergy, the role of the volunteer is to be focused most with “how to *be* in the world,” since every act they perform is tinged with the “significance of life in the most profound sense” (Foster et al. 6). Further, the reflection of many focus group members, when speaking about the how and why of their service, imply that being a hospice volunteer *is* a vocation. In other words, their service is a calling that gives meaning and shape to their lives and is of value to the community and individuals in their care. As Brittany so aptly put it, “I have...been trying to discern my call and hospice seemed to be a good fit for what I was learning.... You’re helping people and that’s what I like to do. As others have said, the job is a job and I needed something more” (RVH Volunteers 25 March 2014).

In a way, being a volunteer at RVH is an ongoing apprenticeship that includes the initial 21-hour training, a required annual skills day, monthly support meetings that often introduce new material pertinent to their role, as well as workshops the volunteers are encouraged to attend. However, the volunteers are not involved in training that seeks the depth needed to provide more comprehensive spiritual care described in the second (or even first) level of Rumbold’s scheme noted earlier. The volunteer coordinator supervises the volunteers, though oversight is more casual or informal and is not directed by a learning plan or covenant, or particular learning objectives (except for the initial training). Feedback is also given regarding field notes and some circumstances regarding patient issues and care, and reflection takes place at times in the monthly support meetings. Nonetheless, there is little or insufficient comment and training regarding direct spiritual care of the patient, especially concerning issues of guilt or forgiveness.

If it is important for the volunteer to become a spiritual generalist and involved in

spiritual care of the patient on a meaningful level as described above, then an apprenticeship involving all three areas identified by the Carnegie Foundation study is desirable. There also needs to be a way for adequate supervision to be provided, perhaps through collaboration between the Volunteer Coordinator and the RVH Chaplain. It is also possible to use professional or volunteer chaplains in supervisory roles, depending on their availability, expertise and experience.

Even if it is not possible to provide an apprenticeship in such a way, more thorough training is critical for volunteers to gain the necessary knowledge, skills and identity to become a spiritual generalist in its most basic form. Doing so will enrich spiritual care for patients, especially regarding critical areas like guilt, regret and forgiveness. At the very least, the volunteer will be able to make appropriate and better-informed referrals to those who provide comprehensive spiritual care. At best, volunteers can become vital partners in the spiritual care of patients, especially concerning matters that so deeply affect a person's spiritual health and wellbeing.

Cognitive apprenticeship: What do they need to know? The volunteers at Ridge Valley Hospice include office workers, teachers, engineers, hairdressers, social workers, clergy/religious, nurses, factory personnel, homemakers and others, either retired or still active in their occupations. So they come to their work with hospice employing an array of knowledge and experience that is already of benefit for the needs of the patient. However, there is much the volunteers need to learn through didactic means, face-to-face encounter with patients and families, or through shared stories and learning with colleagues and staff. Of course, with any endeavor there is much to "know," particularly regarding matters touching on spiritual health and wellbeing, and

even more so when dealing with issues of guilt and forgiveness. In the following pages attention will be given to critical areas of knowledge helpful to the volunteer involved with spiritual care of the patient. In some cases, the RVH volunteers receive sufficient instruction in these areas and have a chance to put into practice what they have learned, though additional instruction could enhance practice. In other areas, more training is desired and needed.

THE NEEDS OF THE PATIENT. The word “hospice” is derived from the Latin *hospes*, the same origin for hospital and hospitality. Relating to a person as a guest, or welcoming the stranger, is at the heart of each of these concerns. Understanding the volunteer/patient relationship in this light speaks to a level of involvement beyond ordinary discourse and encounter. As Sulmasy articulates, “to be hospitable is to make one’s guests feel important, worthy of one’s time and effort” (*The Healer’s Calling* 50). To be hospitable is to treat the relationship with care and significance. Those who decide to volunteer with hospice, like those at RVH, often come with an intuitive grasp of this wisdom, though training and experience with patients helps the volunteer to internalize this critical practice.

If, as Kushner claims, the two major issues for the dying person is fear of pain and loneliness, or abandonment (Kushner “Religious Resources for Healing” 4), then practicing hospitality is incredibly important to the role of the volunteer, if not the most essential thing they do. Becoming a companion with someone as they journey toward the end of life helps the patient know they are important, that their life has meaning, and that they will be cared for and supported. However, there are other needs of the patient that are important for the volunteer to be aware of, as well as practices and knowledge that will enhance the volunteer’s hospitality and service to the patient. Dealing with these needs and issues can be the basis of trust and deeper relationship. Such relationships may also allow the volunteer to assess, and perhaps help with

deeper spiritual issues like guilt and forgiveness.

Of course, there are many patient needs that are ordinary or commonplace, like making a meal, caring for a pet or reading to the patient. However, there are other needs that volunteers should be aware of that are directly or indirectly related to the spiritual and existential concerns of the person facing the end of life. The initial training for the volunteer addresses some of these matters, like knowledge of terminal illness, comfort measures and pain management. Some knowledge of these issues is important to the spiritual and existential spheres because physical and spiritual are not divorced from one another. Holistic care has to do with more than treatment, and is concerned with the interrelated nature of the spiritual and physical (and emotional, social), especially as one nears the end of life. For example, dealing with a terminal disease and related problems often leads to the patient questioning values, relationships, beliefs and their own identity (Todres, Catlin and Thiel). Central to some of these concerns may be the patient's relationship with God, struggles with grief and loss, or feelings of guilt (Puchalski et al.) Having knowledge of these issues and their interrelation allows the volunteer to be more open and available for the patient if needed, or to pass along concerns to appropriate members of the interdisciplinary team.

The patient also needs caregivers, including the volunteer, to understand that pain is not just physical. Puchalski, a physician and pioneer in the integration of spirituality and healthcare, asserts that from her "clinical experience, I have found that spiritual suffering underlies most of the pain that patients and their families experience" ("The Role of Spirituality" 21). In fact, pain can be manifested in a variety of ways with its source in emotional, physical, relational and spiritual distress. An awareness that pain is not just physical will help the volunteer to be more attentive to possible clues that assist the volunteer in addressing these issues in a general way, or

passing along correct information to a spiritual (or other) specialist.

Patients are also in need of basic emotional and spiritual support, helping them to maintain a sense of self-respect and self worth in the face of a debilitating/terminal disease, as well as maintaining a connection with community and the world around them (Yi-Yung 715-717). Consequently, offering consistent and dependable care, keeping promises about visits, and being attentive and empathetic listeners are important ways to meet patient needs. In fact, Thiel and Harris indicate that listening is paramount, especially as patients share stories about their lives: “Story listening, like story telling is an ethical act.... to speak and not be heard is more painful to the teller than not to speak at all” (234). It is through sharing of stories that the patient speaks of the joy and pain in life and is a way to explore and reveal meaning and purpose, relationships and faith, struggles with spiritual or other concerns, or simply to enjoy the company of another that understands or is willing to honor the patient’s life. At RVH, it is evident that the volunteers place a high value on hearing the patient’s stories. What may enhance patient spiritual care, though, is training in identifying signs of spiritual distress or questioning in the midst of these stories.

Another possible need of the patient is for the volunteer to understand that death does not mean the end of hope. In fact, “for the dying person, hope is integral to living with dying” (Puchalski “Spiritual Stages of Dying” 56). That being said, hope is also a belief that is constantly challenged as one makes the journey towards the end of life. Consequently, the volunteer should be ready to encounter various feelings regarding hope, which also includes notions about forgiveness or touches on how a patient may be dealing with guilt. In a way, how one deals with hope is similar to how one may deal with grief and loss, through various stages that may move from hope for a cure or miracle, to acceptance, and then to seeking meaning and

purpose in the midst of suffering and dying (Puchalski “The Role of Spirituality” 19-20).

Similarly, facing issues of guilt and moving toward forgiveness also involve enduring loss, facing difficult truths, acceptance, and seeking meaning in the midst of complicated situations and relationships.

In short, what is vital in terms of patient need is a person or persons who offer care in a trustworthy manner, are attentive, empathetic, and willing to listen and share without judgment. Although patient needs may feel overwhelming at times, especially if they are struggling with spiritual concerns, their needs and struggles are simply part of what it means to be human. As Nouwen suggests, “when we become aware that we do not have to escape our pains, but that we can mobilize them into a common search for life, those very pains are transformed from expressions of despair into signs of hope, [and] through this common search, hospitality becomes community” (93).

SPIRITUAL ASSESSMENT. One of the critical elements of care for the hospice patient is the spiritual assessment, and knowledge regarding this tool would be important for the generalist, as it is necessary for the specialist. As Puchalski et al. put it bluntly, “spirituality should be considered a patient vital sign” (891), and so proper assessment of the patient’s spirituality and spiritual wellbeing is essential for holistic care. Therefore, it is important to have a process and framework for gathering pertinent information regarding a person’s spiritual history and needs. The information can then be used to develop a plan to deal directly with spiritual issues or distress, or in conjunction with a comprehensive treatment plan that includes other physical or social needs the patient may have (Hodge; Rumbold). The assessment can also give indication or guidance regarding whether a person’s spiritual beliefs will help or hinder their ability to cope, or how their spiritual outlook may influence treatment (Handzo and Koenig; Koenig *Medicine*,

Religion and Health).

Not only is the spiritual assessment helpful, it is required by the Joint Commission (aka JCAHO), one of the major accrediting bodies for health care organizations in the United States (Hodge 31; Scott, Thiel and Dahlin 17). The spiritual assessment is also a required practice for hospice agencies as stipulated by the Hospice Medicare Conditions of Participation (“Medicare and Medicaid Programs” 32208). However, neither the Joint Commission nor Medicare stipulates particular requirements for the content of the assessment.

What has evolved over the years is an approach involving screening, taking a religious/spiritual history and a more thorough spiritual assessment. Screening is the most basic stage and includes simple inquiries regarding a person’s spirituality and religious practices. During the screening, which requires basic training to perform, a member of the palliative care or hospice care team may ask about the importance of spirituality or religion to the patient, if they are a member of a particular religious community, and if the resources currently available to the patient are working for them. The religious or spiritual history is usually more in depth and usually includes particular questions that are more specific about resources, a patient’s spiritual or religious background or particular needs and hopes. The spiritual history inventory is usually administered by someone trained to do so, including social workers, nurses or chaplains, those who can also deal appropriately with issues that may emerge. The spiritual assessment is even more involved, and aims to elicit the patient’s story while also discerning needs and resources that emerge, as well as identifying more clearly places of spiritual strength or distress. The assessment is less focused on a particular set of questions and more on a narrative approach, where listening skills are paramount, as well as an ability to navigate the patient’s story and concerns (see Hodge; Puchalski et al.; Scott, Thiel and Dahlin). Administering the spiritual

assessment requires more training and experience and should be handled by a board certified, or highly trained chaplain. However, there are no regulations that prevent other members of the team from administering any level of assessment.

In practice a variety of approaches are taken regarding assessment depending on staffing, training and the quality of assessment tools. At Ridge Valley Hospice, for example, the chaplain manages the initial and follow-up assessments; while nurses and social workers are involved in consistent screening as spiritual needs arise for the patient. The number and variety of spiritual assessment instruments, which are numerous, typically focus on issues like meaning and purpose, grief and loss, guilt and forgiveness, value and dignity, significant relationships and how spiritual and religious beliefs and practices influences the patient's world view (Scott, Thiel and Dahlin; Rumbold). For example, the Rev. Mary Martha Thiel, a board certified chaplain and the Director of Clinical Pastoral Education at Hebrew SeniorLife/Hebrew Rehabilitation Center in Boston, typically employs an assessment model that addresses seven areas: (1) love and belonging; (2) guilt and forgiveness; (3) hope and hopelessness/despair; (4) trust; (5) meaning and meaninglessness; (6) gratitude; and (7) identity, or a person's spiritual need to be known and accepted for who they are (Thiel 26 September 2014).

The spiritual assessment is critical for all members of the team because, if done well, provides keen insight into the patient - their needs, fears, and struggles, relationships and beliefs - as well as potential sources of spiritual strength and meaning. The assessment can also provide valuable information which points to issues of guilt, or the need for forgiveness. Additionally, it may offer pertinent information and direction that is useful for exploring or simply talking with the patient about spiritual issues.

Although RVH volunteers are instructed to avoid religious conversations unless broached

by the patient, it would be helpful for the volunteer to be aware of, and have available, the spiritual assessment, especially if religious issues arise in conversation. To have such access would require training on how to interpret and responsibly make use of the assessment.

Rumbold's model above regarding spiritual care also suggests volunteers could take a more active role, by being involved in spiritual screening or some form of spiritual assessment. Again, appropriate training would be required. In either case, providing instruction to the volunteer regarding the spiritual assessment could be an asset for patient care. With such training, the volunteer would have a heightened awareness of possible spiritual issues, especially those that broach difficult subjects like guilt and forgiveness. They could also be involved in follow up screening in order to identify new issues, or to monitor progress along the way.

SPIRITUAL/RELIGIOUS. At one time the spiritual care of patients typically involved chaplains or other clergy interacting with patients along shared religious commitments and understanding. Or, if not shared, there was a dominant religious context that drove spiritual care. In this context religion was considered broader and more comprehensive than spirituality, if "spirituality" was considered at all. In other words, the spiritual happened within the context of religious tradition and custom. It was less that the two were distinct, and more that spirituality described a critical aspect of religious practice (Rumbold).

However, due to a variety of cultural and societal shifts, there was a corresponding shift in the understanding of spirituality and religion. Spiritual care being offered in health care settings also began to give prominence to spirituality, rather than the religious. Provision of care was still offered by clergy and chaplains, but with less of a "position of ownership of spiritual care to one of participation in spiritual care" (Rumbold 257). Attention to the spiritual health of patients also began to be provided by those outside the realm of denominationally affiliated

clergy or chaplains. Spirituality became the more encompassing term, and this change in understanding and practice had, and has, significant implications regarding spiritual and religious issues that may arise for the patient. This is especially true for traditionally laden matters like guilt and forgiveness⁸ (Rumbold 254-255; Puchalski “The Role of Spirituality” 10).

For anyone dealing with spiritual care, even on the most basic level, it is important to have some grasp of these differences between “spiritual” and “religious,” as well as other related wisdom regarding these concepts. Such knowledge could be especially helpful for the RVH volunteer. As indicated in the introduction, the primary religious milieu for the patients and volunteers associated with RVH is Christianity, informed by traditional mainline Protestant, Anabaptist and Roman Catholic perspectives. Becoming aware of nuances regarding “spiritual” and “religious” could introduce the volunteer to broader ways of understanding what patients may be feeling, believing, thinking and needing regarding their spiritual selves, and that spiritual needs and beliefs may not fit neatly into traditional religious concepts and practice.

As is the case with other aspects of spiritual care, there is no standard definition of spirituality. The literature is fraught with numerous definitions (for example, see Hodge 28; Puchalski et al. 887; Puchalski “The Role of Spirituality” 10-11; Handzo and Koenig 1194; Robinson et al. 720; Puchalski “Spiritual Care” 45; Sulmasy “The Healthcare Professional” 103; and Mann 119). Some define spirituality as being explicitly oriented toward God or a higher power, while others address spirituality in broader terms like meaning and lived experience with no mention of a divine being or the sacred. The definition to be used here comes from the Consensus Conference, which involved a group of over forty participants that included

⁸ See informative survey regarding move from religious to spiritual and implications for pastoral/spiritual care in Rumbold, esp. 252-257.

chaplains, nurses, physicians, academics, social workers, psychologists, pastors and others related to health care: “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchaski et al. 887). The significant could be God, or could also be family, a particular social cause, organization or a person’s vocation.

“Religious,” on the other hand, is somewhat uniform in the way it is defined, being seen as “a group’s enculturation of an organized system of beliefs, texts, roles and practices related to spirituality” (Robinson et al. 720). The religious, then, is more corporate and communal, while spirituality is often focused on the individual and a personal search for meaning. “Religious” has to do with codifying rituals and beliefs, where spirituality involves what meaning the person gives to a particular ritual, how they internally experience a practice like prayer or Eucharist, or how things like nature or service affects their spirit. The religious is more external, while spirituality deals more with one’s inner beliefs. Everyone can be considered spiritual, but not everyone is religious.

Of course, discussion of the differences between spiritual and religious has gained popularity and traction in our postmodern context. Although there may be some overlap and connection between the notions, it is understood that these concepts or categories are indeed distinct (Hodge 28). Puchalski mentions a study of HIV patients that is instructive regarding the differences between spirituality and religion and implications for spiritual health. The study indicated that, “those who were spiritually active had far less fear of death and less guilt about their illness. Fear of death was far more likely among the...religious patients who felt their illness was a punishment from God” (“The Role of Spirituality” 15). In other words, the

“religious” rules or codified beliefs regarding sin and a punitive God led some HIV patients to deep spiritual distress. On the other hand, those who found meaning in, and regularly practiced things like prayer and meditation, or communing with a higher power had a different take on their illness and possible outcomes.

It is somewhat obvious that these distinctions are important in previous discussions of the spiritual assessment and spiritual care. Likewise, paying attention to the distinctive features of “spiritual/spirituality” and “religious” are important for exploring guilt, regret and forgiveness. Such awareness may help the volunteer to listen to a patient with greater care or attentiveness, help discern whether their concern is religiously or spiritually motivated, and respond appropriately. For example, several in the focus group experienced a patient asking, “Why am I still here, why hasn’t God taken me?” A “religious” understanding might lead the volunteer to encourage the person to pray, because God answers prayers. Another response that might connect with a person’s religious instruction or upbringing might be, “well God has a plan and is not done with you yet.” Perhaps the volunteer believed that the patient is “ready” and is just expressing their readiness to meet God. These responses are good and may be what the patient needs to hear, or may be what he or she was taught to believe. However, underneath the patient’s question may be a feeling of guilt or frustration with God – guilt because they are still alive and a burden to their family, or a drain on the finances, or because they have always been the caregiver and their prolonged life is somehow undermining their loved one’s wellbeing; frustration, because God is not acting in the way the patient thought a loving God would act. It matters to the spiritual health of the patient which response describes their inner spiritual state. Consequently, it would be beneficial to probe slightly to determine where the patient is at, rather than simply accepting or suggesting an answer that is comfortable and straightforward, yet

misses out on discovering possible struggle or spiritual distress.

Finally, Rumbold rightly suggests that this distinction between spirituality and religion means any conversation or sharing in the context of spiritual care cannot assume that patient and caregiver are using common religious beliefs and values (255), even if both patient and the spiritual care provider are part of the same religious denomination or group. Therefore, it is critical that anyone involved with even basic spiritual care should be aware that attentive listening, asking pertinent and appropriate questions, and finding a place of clarity is critical to patient spiritual health.

SPIRITUAL VS. RELIGIOUS. One of the fastest growing groups on the religious landscape in the United States is the *nones*, or those unaffiliated with any religious organization. This group includes atheists as well as those with personal belief, but no religious association. *Nones* are also often described as being “spiritual, but not religious.” What is critical for the discussion for this project is the consideration that *nones* require a different sort of language or approach when it comes to spiritual assessment and those matters that often occupy those who are dying. It may be important for those providing spiritual care to ask questions like: Is it possible to consider issues of guilt from a non-religious viewpoint, and if so, are spiritual care providers adequately trained regarding alternative perspectives? What resources are available to a dying patient regarding spiritual issues like guilt and forgiveness when they have no relationship to a community of believers, or have little spiritual connection, or are more secular in their understanding? Do current models of assessment take these and similar possibilities into account and how will assessment and spiritual care need to change if trends continue?

Although future considerations are important, and trends will need to be monitored and investigated, deep exploration of the broader questions suggested above are beyond the purview

of this project. Even so, it is important to mention that feelings of guilt and a need for forgiveness can exist without linking these notions inextricably with religious concepts. Existentialists of the late nineteenth and early twentieth century (e.g., Camus, Nietzsche) explored notions of guilt while purposely moving the conversation away from traditional religious (primarily Christian) belief and ideas regarding hope, which they considered inadequate to address the human person's existential angst. Other philosophers and thinkers, from ancient to modern times (e.g., Aristotle, Greenspan) have also considered guilt and shame without a connection to Christian concepts of God, or any link to explicitly theological understandings.

In light of this discussion, it might be helpful in training for spiritual generalists to address the cultural context in which *nones* and particular religious matters, like religious pluralism, are understood. In other words, a brief description of the cultural shifts from traditional to modern/scientific to postmodern in the context of religion and spirituality may be of value. It may also be useful for volunteers (and staff as well) to realize that patient beliefs and concerns can be located in traditional values or postmodern views, or be a mix of all three broad categories.⁹

Whether such training regarding cultural shifts would be helpful or not, current practice and understandings are important to consider. This is especially true regarding spiritual concerns like guilt and forgiveness, which are often defined by volunteers at RVH, and other hospice team members alike, in ways steeped in religious tradition or that are culturally bound. Such

⁹ There are countless resources regarding postmodernism and the cultural, religious, philosophical and social shifts that have occurred in society. Although her treatise is oriented towards the primacy of Christianity, *How Postmodernism Serves (My) Faith*, by Crystal L. Downing, is an accessible description of the cultural shifts described above as well as postmodern views of truth and religion. Some of her examples and illustrations could possibly be adapted for training.

understanding, while helpful with most patients they serve, can be a detriment to others who may be “spiritual, but not religious,” or without faith. In fact, in one focus group meeting when we were discussing forgiveness, John touched on this concern: “we all know the word forgiveness and we should forgive. ... every [religious] organization is brought up in forgiveness and love or kindness, but I’m still waiting for this one big challenge where this guy says, ‘there is no God’” (RVH Volunteers 1 April 2014).

Although a different approach to patient care seems prudent, there is little to no research at this point that deals with language and treatment regarding spiritual care of the “spiritual, but not religious,” or those considered atheist or who are simply apathetic regarding religion or spirituality. Hodge does highlight criticisms from the United Kingdom (UK) that question whether a patient’s spiritual concerns even need to be addressed. The argument, put simply, is that in an increasingly secularized society, religion and spirituality are no longer important to consider in the treatment and care of patients. Further, even though nearly half of the UK’s population indicates they do hold certain spiritual beliefs, proponents of “secularization theory” suggest these beliefs do not shape persons in a way that is distinctive from secular society on the whole. Hodge provides counterarguments that chide the proponents of secularization theory for so easily dismissing the importance of spirituality or religion in a person’s life, especially when there is a health crisis or terminal illness. He also presents reasons why it is important to consider a person’s spirituality, like respecting a patient’s personal autonomy, how spirituality shapes a patient’s worldview or offers resources for coping and wellbeing (28-33). However, still left unaddressed in Hodge’s work is the concern about language or different treatment methods in light of a shifting and changing spiritual landscape. The secularization theorists seem to abandon the need for ways to deal with issues like guilt and forgiveness at all, while Hodge

simply reiterates that a patient's spirituality and religious beliefs are important to take into account.

Even though some would argue that the United States is nearly like Europe or the UK, or becoming like them in terms of spirituality and religious affiliation, an NPR report on recent PEW research suggests otherwise. Even though there has been a significant decline (8%) in those who identify as Christian over the last seven years (the span of PEW's comparative study), and a significant increase in the unaffiliated (6%), the research data from the study paint a picture that is different from the religious environment in Europe. Further, the study, which seems to indicate a rising tide of those who dismiss religion (or even spirituality), actually presents a far more complicated picture. For example, the increase in the unaffiliated seems to be a result of several possible factors say the commentators on the PEW research, the most significant being politics. The data suggests that in the United States the unaffiliated are primarily liberal and moderate persons who, as more conservative churches and religious groups became louder regarding issues like abortion or gay marriage, simply decided to leave churches and religious organizations. Even though they leave church, many are still involved in social causes and service. The study also showed that many of the now unaffiliated was at one time a part of a religious organization and that a significant number are indeed spiritual. Put another way, the data suggests many pray, believe in God or a higher power and engage in religious or spiritual ritual, but do not go to church (Smith and Hout). Nonetheless, even though the PEW research points out the shifts in religious affiliation, it does not address the prevailing issue of the impact on spiritual care, or how best to deal with issues like guilt and forgiveness.

Thiel suggests what seems to be the prevailing mood at this time, that for those who are "spiritual but not religious" expression of their spiritual needs, beliefs and fears still rely on

culturally bound concepts and language, even if they simply reject them as pertinent or part of their belief system (26 September 2014). For example, a patient may reflect negative views of God and guilt based on harm they experienced through the religious tradition of their youth. However, the patient's anger may be at the church and not God. Coming to this understanding may allow for healing to occur. For others, moving from conversation about God or church to a focus on meaning and purpose may elicit feelings that touch on guilt or shame, or a need for forgiveness that may still reflect religious tradition or culture.

Since there is insufficient research at this time that offers direction or help, it might be best to consider the attitude and approach suggested by Tiew et al. regarding spiritual issues, including guilt and forgiveness: "Indeed, in contemporary society, individuals may have a wider view of spirituality than just their traditional religions and cultural beliefs. Individuals may subscribe to a particular religion but be flexible in the way they pursue it and not exclude the beliefs of others" (2931). Or, in the case of the unaffiliated, they may construct a personal belief system that includes the tradition that was part of their formation as children and youth, or one eclectic in nature, borrowing from other faith traditions or their interpretation of them. In fact, the religiously affiliated may do the same.

Perhaps in time, new research and language will emerge as the religious (and spiritual) landscape continues to shift, especially if changes are dramatic. However, for the time being, approaches and ways of conceptualizing issues like guilt and forgiveness have a wide enough variety in religious, philosophical and secular thought, that current scholarship and reflection are still critically important for addressing the spiritual and religious needs of hospice patients in the United States. Again, what is important for training is being attentive to the patient, listening well, and being careful regarding assumptions about patient stories that touch on important

spiritual themes and concerns.

GUILT, REGRET AND FORGIVENESS. If it is possible that volunteers, overseen by trained clergy or religious professionals, can play a significant role in addressing the spiritual wellbeing of the patient regarding guilt and forgiveness, then some attention to these concepts and their relation needs to be given, beyond what has already been stated in previous chapters.

As noted previously, the majority of patients in the care of Ridge Valley Hospice is Christian or is heavily influenced by Christian tradition and culture. Therefore, the discussion here will utilize the wisdom of several Christian authors, though other perspectives will be included. However, as the previous discussion regarding the “spiritual, but not religious” indicated, it is important that the volunteer (or chaplain for that matter) be careful in their assumptions regarding the beliefs held dear by the patient. Even so, it is necessary to approach guilt and regret from some vantage point and, at least for RVH, using a Christian perspective is certainly understandable and reasonable. This section, then, will explore perspectives and aspects of guilt and regret as a basis for further reflection, and as a foundation of knowledge to help navigate or simply better understand issues that patients may face.

Guilt and shame. As a beginning, it is helpful to return to Vanier’s descriptions of guilt, and related notion of shame, noted earlier. He indicates that psychological guilt is the kind of guilt that “is induced in us by others, those who have made us feel that we are without value” (136). This type of guilt is also known as “shame” and is to be distinguished from moral guilt, “the one we induce in ourselves after having done something wrong” (136-137). Moral guilt arises when we hurt another person, commit a crime or take part in actions that cause damage to things or people. Psychological guilt, on the other hand, “is the feeling that can overwhelm us when we feel rejected as individuals” (137). Kushner agrees and puts it plainly, “Guilt, they say,

is a judgment we pass on ourselves. It is a voice inside our heads telling us that we did something wrong. Shame is a sense of being judged by someone else.... Guilt, [then], is a product of an individual conscience.... Shame is the product of community” (*How Good Do We Have to Be?* 39-40). Further, although Vanier makes a distinction between a persons’ culpability for doing something wrong and claims about their worth, he also believes that guilt and shame, as he describes it, can “feed into each other” (137).

Brené Brown, a sociologist whose research focuses on shame and vulnerability, expresses yet another view that is both consistent with and slightly different from Vanier and Kushner. Her research makes a distinction between guilt and shame as well. For her, guilt expresses the idea that “I did something bad,” while shame says “I am bad” (71). Guilt arises when we do something that does not match up with our values and motivates us, even if it is uncomfortable, to make a change (72). Shame, on the other hand, “is the intensely painful feeling or experience of believing we are flawed and therefore unworthy of love and belonging” (69). For Brown, guilt is more a helpful emotion that leads one to feeling remorse, and making apologies or amends. Shame, though, is insidious and destructive. In fact, she asserts that, “researchers don’t find shame correlated with positive outcomes at all...[nor is it] a helpful compass for good behavior” (73). What is also interesting in her portrayal is that her definitions of guilt and shame are consistent with postmodern sentiment. That is, guilt is a dissonance between our actions and our values, and our values do not have to be related to a religious point of view. The same is true for shame, though her definition and commentary could easily come from a theological text and mirrors some of Kushner’s remarks and criticisms.

These views are not the only ones that may reflect the basis for a patient’s feelings and concern. Ancient Greek thought has long influenced our current views regarding a number of

issues including guilt. For example, Aristotle considers shame in *The Nicomachean Ethics*, especially as it relates to virtue, but his analysis, consistent with ancient Greek thought, makes no distinction between guilt and shame (140-141; Greenspan 58). Similarly, there are religious and other views that also make little or no practical distinction between the two. In some Christian communities, guilt is best described as an existential state or condition, as intimated by Westphal (69-78; also, see discussion in Chapter 2: Literature Review), and is the focus of sermons on many a Sunday around the United States. In this view the words sin, guilt and shame are practically interchangeable and express the belief that all are in a state of sin, or separation from God, and thus are (and will be) disobedient and guilty. The hope is that as one hears the Gospel, they will become aware of God's grace, repent (*metanoia*: turn around), and be forgiven by God. Guilt, then, is a state of being before God, and sinful actions, or deeds that lead to a person feeling a deeper sense of guilt or shame, arise from this imperfect state. Kushner believes that this view of guilt and shame is harmful and inappropriate, since it concludes we are always imperfect before God, and thus would always have reason to feel guilty. He advocates for a more positive view of guilt that can lead spiritual health and wellbeing (*How Good Do We Have to Be?* 39-42). Even so, this view of sin may be at the heart of what a patient is dealing with, and the ability to appropriately identify such feelings can be critical for spiritual care.

The attitude that Kushner criticizes is also at the heart of why some have such difficulty dealing with guilt and regret. For example, B.B. Taylor has pointed out that some view guilt as an archaic tool still being used by the church for control of its adherents or “keeping people in line” (*Speaking of Sin* 28). She tells of a woman who was proud of keeping her daughter from the influence of the church. Schooled by nuns who had “bullied her for years in the name of God,” the mother “vowed to protect her own children. ‘My daughter doesn’t know Moses from

Goliath,’ she says with some pride, ‘but at least she grew up without guilt’” (*The Preaching Life* 7). This is a stinging indictment of “guilt,” or at least a kind of guilt viewed in unhealthy and mistaken ways. Yet, it is understandable why the mother, and others like her, would like to jettison guilt and shame from our language, and believe they undermine a healthy understanding of self, relation to others and even our relationship to God or a higher power. These feelings regarding guilt also make clear why some do not want to speak with a chaplain or spiritual counselor. Instead they express their hurts and feelings to a nurse, or social worker, or volunteer – or ignore, bury or set aside such feelings altogether.

However, ignoring feelings that can be described as guilt or shame can be harmful. As Bell so eloquently claims, “our junk will inevitably catch up with us. It’s like maybe not that day, maybe not the next day, maybe not for a while, but give it enough time it always finds us” (“Lump”). In other words, our deep-seated, nearly always avoided guilt will eventually affect us and will cause an even greater spiritual disease, often becoming destructive not only to our own spirit, but distressing and harming others. This could have been true of the patient Shauna visited frequently who shared how she had been mean to her children all of her life. In their encounter with one another, which Lois described as a kind of “confession,” the woman was able to speak of her “junk,” knowing that Lois would be nonjudgmental and allow her to share her story. Although it may have been helpful in the long run to her, and to her children, to move to a place of healing, this did not occur. On the surface it appeared she was unable to escape her past and brokenness and whatever feelings they produced within her.

Bell and G. Taylor clearly speak to this sense that we cannot escape the “junk,” the sin, the guilt, the regret. In fact, they suggest we would serve ourselves better to recognize that these matters are well rooted within us, and consider it a sign of health to understand and acknowledge

the stuck places in which we find ourselves. “The past keeps coming back,” proclaims G. Taylor. “Dr. Fodsick long years ago told of a muddy road in Vermont where the sign said, ‘Choose well your ruts. You will be in them for the next five miles’” (30). This suggests that guilt is present in deep-rooted and subconscious ways and is an issue or condition that resists an easy fix. Therefore, guilt is a persistent teacher seeking a depth of faith, honesty, courage and relationship with something or someone greater, or beyond, ourselves. In fact, as Brown suggested, guilt can be a motivator, a driving force behind changes needed in our lives. Guilt not only helps us to recognize what is wrong, it can also point us in the direction of faith or healing. Or, as Coffin put it, “*Guilt is to save us, not destroy us*. It saves us by keeping us honest, and by pointing us toward forgiveness” (117).

Forgiveness. Coffin, Brown, and others highlight the need for embracing guilt in healthy ways, for to do so points us in the direction of forgiveness, healing, restoring relationships and making amends. It is important, then, to understand that there is a connection between guilt and forgiveness and that guilt can lead to the positive work that is necessary for spiritual health. In fact, those who speak about forgiveness, but not guilt or shame, may be missing a critical connection and pathway to healing. Barbara Brown Taylor gets straight to the heart of the issue when she proclaims, “the only thing guilt is good for is to move us to change. If it does not do that, then it’s just a sorry substitute for new life” (*Bread of Angels* 111).

Dealing with guilt can be a pathway through hurt and grief that can lead to forgiveness, new life and our true humanity. This is especially true for the person facing a terminal illness or the end of life. Vanier, in speaking about forgiveness, asserts, “that the forces of life and the desires for communion are greater than the forces of death and hatred. At some moment in each of our lives there is an event that calls us to freedom and openness” (150-151). The healthcare

field has also recognized this point, and it has been noted in research and literature that forgiveness and reconciliation are prominent concerns for patients who are dying (Carson and Koenig 130-131; Puchalski “The Role of Spirituality” 20-21). Although the patient may have had other moments in their life where facing guilt and moving toward forgiveness were important, it is not difficult to understand that the end of one’s life will certainly be an “event” that calls one to even more openness and freedom.

In their treatise, *The Book of Forgiveness*, Desmond and Mpho Tutu speak of the South African concept of *Ubuntu* as a way to address the importance of forgiveness, a concept that also brings some clarity to further understanding the connection of guilt and forgiveness:

Ubuntu.... is the philosophy and belief that a person is only a person through other people. In other words, we are human only in relation to other humans. Our humanity is bound up in one another, and any tear in the fabric of connection between us must be repaired for us all to be made whole. This interconnectedness is the very root of who we are. (8)

In this view, which has connection to Christian theological themes and other ways of seeing creation and the world, guilt would be the way in which we recognize and acknowledge the “tears in the fabric of connection between us” and forgiveness deals with the repair and embracing our interconnectedness. Although this may seem to be a rather simple statement and concept to grasp, it is universally recognized that dealing with guilt and moving toward forgiveness is a difficult path. However, if we believe interconnectedness is integral to who we are, whether that connection is to one another, God, or creation, then dealing with guilt and walking the path of forgiveness is essential for spiritual wellbeing. As the authors assert, “with each act of forgiveness, whether small or great, we move toward wholeness. Forgiveness is

nothing less than how we bring peace to ourselves and our world” (6). Although Tutu and Tutu speak clearly regarding the noble consequences of forgiveness they also, like other authors, mention other positive spiritual and physical health effects of forgiveness for patients in general, especially those who are dying (Tutu and Tutu; Carson and Koenig; Puchalski “Spiritual Stages of Dying;” Puchalski “Forgiveness: Spiritual and Medical Implications”).

Tutu and Tutu also speak of forgiveness in ways that resonate with the aims of hospice care. According to the authors, doing the work to forgive another or to be forgiven requires vulnerability, telling one’s story truthfully (which includes honesty about issues of guilt), active listening and internalizing what another has said. Forgiveness also leads to healing and dignity, as well as a greater sense of wholeness for the person and the world.

Even though they admit that their model for forgiveness is Jesus, Tutu and Tutu claim that, “forgiveness does not require faith” although faith makes it easier for some to forgive (57). However, for many, including the patients and volunteers associated with Ridge Valley Hospice, guilt and forgiveness are rooted in religious/spiritual understandings and interpretations, and specifically Christian ones. Namely, one’s ability to face guilt and forgive is rooted in the actions and initiative of God. As Nouwen asserts, “this hope [in the promises and activity of God], stretches far beyond the limitations of one’s own psychological strength, for it is anchored not just in the soul of the individual but in God’s self-disclosure in history” (76). Because God has forgiven and shown us how to forgive in and through Jesus, we too are able to face our guilt, ask for forgiveness or grant it, and move toward deeper healing and release. This view of forgiveness is not limited to the traditions and culture of RVH patients and volunteers. Numerous members of the health community also use explicit religious language when speaking about the spiritual and medical implications of forgiveness (e.g., Carson and Koenig; Sulmasy

The Healers Calling). Indeed, as Puchalski notes, “forgiveness is the act of being restored to a good relationship with God, others and self, following a period of sin or alienation....

Forgiveness brings wholeness back to these relationships” (“Forgiveness: Spiritual and Medical Implications”).

Of course, anyone who is to deal with the spiritual care of the patient needs to be aware that differences exist in how a patient may understand forgiveness, and that these perceptions depend on their religious tradition, upbringing, or their personal interpretation of these matters. In other words, forgiveness, like guilt, can be seen from a variety of perspectives, even for those of the same faith, and these heart felt views can arise from one’s tradition or even another that the patient has appropriated.

To get a grasp of some of these differences and nuances regarding forgiveness, it is helpful to consult Simon Wiesenthal’s classic book, *The Sunflower*. In this narrative, Wiesenthal shares a true story of his time in a concentration camp in Nazi Germany. In the story, an SS officer, who has committed heinous acts against Jewish women, men and children, asks for a Jewish prisoner to see him as he lays on his deathbed. Wiesenthal is chosen, and the Nazi soldier shares his story and asks Wiesenthal to forgive him. What follows is Wiesenthal’s reflection and response. Years later, Wiesenthal invites others to consider what they would have done and, as the title specifies, to contemplate “the possibilities and limits of forgiveness.” An updated edition of the work includes some of the original articles as well as over thirty new responses. The essays are from various scholars, theologians, religious leaders, political leaders, psychiatrists, writers and others from various religious traditions and experience. The multitude and variety of deliberations cannot be summarized here, but suffice it to say that Jewish, Christian and Muslim understandings are typically different, and that there is even variety within religious traditions.

Further, there is much discussion as to whether Wiesel has the authority to offer forgiveness in the name of others the soldier has killed, or if the Nazi soldier can be forgiven because the victims are no longer alive. Both views challenge Christian understanding, and also touch on important issues regarding authority, especially Roman Catholic sacramental practice and belief. One interesting essay is from an atheist who essentially indicates guilt and forgiveness are “irrelevant,” for him since both are religious or theological categories. Instead, he speaks of “worldly justice” that must occur for the Nazis and their crimes (Wiesel 107-109). In another response, Eva Fleischner cautions that some Christian beliefs regarding forgiveness come from a mistaken view of key New Testament passages, especially those from the Sermon on the Mount. For example, the Lord’s Prayer and its admonition to forgive does not mean, “we are to forgive anyone and everyone, whatever the wrong done to anyone.... [Instead] Jesus challenges *me* to forgive evil done to *me*.... Nowhere does he tell us to forgive the wrong done to another” (Wiesel 140-141).

Interestingly, the Amish community bases their extraordinary ability to forgive others (even *anyone and everyone*) on passages from the Sermon on the Mount, especially the Lord’s Prayer. In fact, there is a strong sense that they will not be forgiven by God if they themselves do not forgive. Although the ability to forgive can be viewed from an individual perspective, there are also strong communal aspects regarding forgiveness among the Amish. In fact, Kraybill, Nolt and Weaver-Zercher assert that “the core value of Amish culture is community” and that key values for their life “require yielding to the collective wisdom of the community” (93). This sense of communal initiated forgiveness was clearly evident after the Nickel Mines, Pennsylvania shootings in October 2006. Other Anabaptist traditions, like the Mennonites, also practice a communal type of truth telling (confession) and forgiveness, even within the context

of worship (Director of Pastoral Care 9 July 2013).

In most Christian traditions, including those mentioned thus far, attention to forgiveness brings us again and again to an intense focus on the cross. For it is at the cross that guilt and sin are met by God's profound statement of forgiveness, where "the cycle of wrong came to its appointed end in the crucified body of Jesus..." (Rutledge *The Undoing of Death* 125). Those who profess a Christian faith, then, are able to face guilt, confess sin, and know that God will offer healing for our souls - and new life to the weary, the downhearted, the guilty, and those who are oppressed by shame. As B.B Taylor puts it, "Christ...took all the meanness of the world and ran it through the filter of his own body, repaying evil with good, blame with pardon, death with life" (*God in Pain* 40).

Traditional Christian belief also asserts that God's forgiveness is intimately connected to God's love for humanity. Indeed, scripture teaches that nothing can separate us from the love of God in Christ Jesus (see Romans 8:37-39). However, there are differences among Christian adherents regarding the limits of that love and forgiveness. In his book *Love Wins*, Rob Bell appeals to the prophets who emphasize again and again God's faithfulness, love and reconciliation. Further, according to Bell, the prophets and other writers in the Hebrew scripture "are quick to point out that [healing, love and reconciliation] isn't just something for 'God's people,' the 'chosen,' the 'elect,'" but for everyone – that "God will be united and reconciled with all people..." (88, 100).

In a way, Bell echoes Julian of Norwich, a fourteenth century mystic, who broke new ground in her time regarding ideas of God's love and forgiveness. Her insistence that in the end, "all manner of things will be well," and the way she deals with God's wrath and sin and the culmination of God's salvation history, was definitely in opposition to the view of traditional

theology espoused by Augustine and other theologians who influenced fourteenth century Christian thought. Augustinians and other Christians in that time (and today) asserted there would be those in humanity that would receive the grace of God and those who would be damned. In *Showings*, though, Julian reflects an encompassing love of God that ran counter to a focus on damnation, purgatory, and judgment as ways of addressing problems in society, or in treating the human condition. To say that “all will be well” for all humanity expresses optimism that focuses less on the “justice of damnation” and more on the gracious will of God. Julian experienced the teaching of God that humanity was of utmost value and that God focuses less on what we do and more on who we are (John-Julian 6).

However, Julian’s notions also have more to do with the culmination of history, or a person’s ultimate destiny, rather than day-to-day experiences. In other words, to speak of God’s love and salvation does not mean that daily problems and struggles will disappear or that “all things will be well” every moment of every day. However,

one of her most telling and central convictions is her orientation to what one may call an *eschatological secret*, the hidden dynamism which is at work already and by which “all manner of things shall be well”.... Actually, her life was lived in the belief in this “secret,” the “great deed” that the Lord will do on the Last Day, not a deed of destruction and revenge, but of mercy and of life, all partial expectations will be exploded and *everything* will be made right. It is the great deed of “the end,” which is still secret, but already fully at work in the world, in spite of all sorrow, the great deed “ordained by Our Lord from without beginning.” (Merton, *Conjectures*, 211-212)

Many Christians, though, would disagree with this sense of universal salvation. There

are those who would agree with the famous preacher, Garner Taylor, who stated clearly that there is a “final exam,” (247) a final judgment: “It is possible, I believe, for one to refuse the offerings of grace...to look upon [the Lord’s sacrifice] so casually and indifferently that one at last becomes too spiritually desolated, too isolated from spiritual reality to recognize the voice of God” (249). Even though the love of God is ever present and seeks out the heart of all people, there are some who can reject this love, this forgiveness and be eternally separate from God. This notion of God’s damnation or forgiveness, or our choice of one or the other, is especially of concern for those who are facing death.

Coping with guilt, shame, regret and forgiveness. It is critical to understand, then, that views of Christian patients regarding guilt and forgiveness can be different, with each view steeped in scriptural, cultural or personal understandings steeped in tradition or affected by modern or postmodern viewpoints. Knowing there are differences like these may help the volunteer to navigate conversations and may serve as a warning regarding assumptions about a patient’s beliefs. It is also important to understand that issues of guilt and forgiveness are connected, not only to patient’s relationships with family and others, but also to the their ultimate destiny and relationship with God. This struggle was quite evident for Barbara’s patient who continued to seek her counsel regarding “what to believe” in spite of time spent with a chaplain and priest. Although Barbara offered good responses to the patient, drawing him back to his own feelings about beliefs, she indicated more knowledge and training could have been beneficial and led to more fruitful conversation (RVH Volunteers 1 April 2014).

Brown’s definition of shame alerts us to another dynamic that may underlie a patient’s feelings or spiritual distress and need for healing. Again, for her, guilt and shame are not the same, and recognizing the differences are critical to how one responds to these emotions. Brown

asserts that everyone has experienced failure to live up to an ideal or value, or has done, or not done something that has caused hurt to another or prevented one from reaching a goal.

According to Brown, guilt is a positive response to these feelings and leads a person to ask for forgiveness (though she does not use this terminology) or do something to create positive change or which makes amends. For her, the feeling of guilt is linked to the recognition we have done something wrong and creates the desire to make the situation right. Shame, is a feeling that the thing we have done makes us a bad person. In a description that is different from Vanier and Kushner, Brown asserts that shame arises because we fear disconnection, or rather, “it’s the fear that something we’ve done or failed to do...makes us unworthy of connection” (68-69). This fear also leads to feelings that can further separate us from others. She stresses as well that shame gains power when a person’s story or truth is left unspoken or unexpressed. Therefore, the antidote for shame is not forgiveness, but is instead, empathy, which is “simply listening, holding space, withholding judgment, emotionally connecting, and communicating that incredibly healing message of ‘You’re not alone’” (81, see Brown’s discussion 59-83).

However guilt and shame are framed and defined, literature and research indicate that listening to a person’s story in an empathetic and non-judgmental way is critical to their process of healing and spiritual wellbeing. Even if the hospice patient believes that forgiveness can only be offered through a priest, the pathway to forgiveness may involve the volunteers’ connecting with the patient, and hearing and holding the person’s story in an empathetic and caring way. Using Brown’s analysis, the volunteer’s role may be helping the patient deal with shame so that they can move to the more positive and healing emotion of guilt, which can lead to forgiveness.

Regret. Just as there are subtleties and differences in the way we define and consider guilt and shame, there is an important distinction to be made regarding guilt and regret. Little

has been said to this point in reference to regret, primarily because research and literature offer so little attention to this subject. However, it may be helpful to return to Cox's distinction mentioned in Chapter 2. If guilt can be characterized as doing something bad, or violating one's beliefs and values, then regret is merely "the feeling of sadness that accompanies choices that do not turn out as intended or that entail trade-offs among key values and ethical responsibilities" (64). Guilt involves fault, while with regret there is no fault or blame that can be placed. So, if the remedy for shame is empathy, and the remedy for guilt is forgiveness, then the remedy for regret could be a discerning ear and helping the patient reframe the story and distress. Again, the example of the WWII veteran is instructive. He may have felt some responsibility for the death of the person who went into battle in his place, and experienced pangs of guilt. However, reframing his experience, helping him to understand that he had no control over the circumstances, or could not be faulted for the other's death, could help him to deal in a different, more healthy way with his sadness and concern.

It is evident that hearing and dealing with a patient's story involves being an attentive, empathetic listener. It is also helpful to be knowledgeable enough (or trained) to make critical distinctions and be aware of subtle aspects of the story that might be useful for the patient's journey towards healing and dignity. In some cases, being aware of the possibilities discussed above may help the volunteer distinguish possible motives and concerns behind a patient's story. Many volunteers at RVH already strive to be empathetic listeners. In fact, making a connection with the patient in this manner was critical to those in the focus group, though the implications and power of such a relationship were not always clear for them.

Of course, numerous scenarios and possibilities regarding a patient's feelings of guilt, regret, shame and forgiveness could be offered as example situations the volunteer may

encounter. It could be that the patient simply wants their story heard and has no need for forgiveness or desire for reconciliation. Perhaps the person asking, “why God hasn’t taken me,” may be harboring feelings of anger at God, and thus beginning to experience guilt associated with those feelings. Another patient may express unease about something they did or did not do, or a sense of being unworthy, calling for the volunteer to offer empathy or to express “you are not alone,” or “I have experienced these feelings too.” There is ample literature that conveys moments like these when healthcare workers are confronted with spiritual concerns of the patient. Some authors offer instruction or propose possible avenues for physicians, nurses or others to help the patient address issues like guilt, anger, abandonment or forgiveness (e.g., Puchalski “Spiritual Stages of Dying;” Puchalski et al.; Kushner “Religious resources for Healing;” Carson and Koenig 129-132). Although most advocate strongly for a board certified chaplain to oversee or provide direct care for the patient, many have experienced opportune moments when patient struggles would not wait for a chaplain visit, or simply when the patient needed more than one perspective. So, even though it is critical to involve the chaplain when such struggles arise for patients, it is important that healthcare workers, including volunteers, have exposure and training so they can offer appropriate help as the patient negotiates these issues. At the least, training is necessary to effectively serve the patient who needs a trusted person willing to hear their story without judgment, and who will be a consistent, non-anxious presence for them as they near the end of life.

VOLUNTEER/PATIENT RELATIONSHIP, BOUNDARIES AND AUTHORITY. Relationship is at the heart of spirituality and spiritual care for the patient. It is essential, then, for hospice team members, and especially volunteers, to make a connection and build trusting relationships with patients. In fact, some have said the volunteer is in a unique position to build such relationships

and that these associations are critical for meeting patient needs (Claxton-Oldfield, MacDonald and Claxton-Oldfield; Planalp and Trost; Worthington).

This sentiment is echoed by RVH Volunteers who also stressed the importance of making a connection and building trust with the patient. Although it is not possible to relate closely to all patients due to health issues (e.g., dementia), personality or time constraints, the volunteers in the focus group felt they were unsuccessful in their mission if they failed to make a connection with the patient. In some instances, the RVH volunteers indicated that they developed friendships with patients, a relationship they believed enhanced their work and provided more comfort and a greater sense of companionship (RVH Volunteer Focus Group sessions).

Although friendship is used at times to describe the patient/volunteer relationship (Claxton-Oldfield, Gibbon and Schmidt-Chamberlain; Dein and Abbas; Focus Group sessions; Volunteer Coordinator 5 July 2013), it is helpful to reflect more deeply on the nature of volunteer/patient relations, especially in connection with spiritual concerns like guilt, shame and forgiveness. Indeed, friendship may not be the best way to describe the close bonds that may form between patient and volunteer. In fact, after discussing volunteer interviews and survey results with the Volunteer Coordinator, a change occurred in the yearly skills review for RVH Volunteers. Fearing that a desire to establish a friendship could cloud the purpose of the volunteer visit, the Coordinator emphasized that the relationship between patient and volunteer was not one of mutuality, and that the volunteer's visit was to be focused on patient needs and not the needs of the volunteer (although there was no indication volunteers crossed lines in this way). Despite these concerns, friendship is the way patients and volunteers sometimes describe the bonds and connections that develop between them, perhaps using the best language they know to describe what is certainly a unique relationship.

Aristotle says that, “friendship is a kind of virtue or implies virtue. It is also indispensable to life” (288). In making such comments, he sets the tone for what friendship is and can be – a good, a virtue, and a relationship of concern, respect and even love for the other. In Book VIII of *The Nicomachean Ethics* he delineates and discusses in depth three types of friendship - utility, or how friends may be useful to one another; pleasure, or the delight one may feel in a relationship with another; and virtue, which has to do with character and mutual goodness, or wishing the good for your friend (253-288; also see Book IX 289-322). In all cases Aristotle believes that friendship involves concern for the other for their own sake and not for one’s personal advantage or convenience. Building on Aristotle’s notions, others see friendship as a relationship of mutuality, care, intimacy and shared values or activities (Helm). It is understandable, then, that some volunteers and patients believe a relationship of friendship can and does exist between them. However, there are limits to the relationship because of the power imbalance between the volunteer and patient. Again, there is also less of a mutuality that one may find between typical friends, since the focus of the volunteer visit is the patient, and not a chance for equal sharing of stories, concerns or other matters that friends may communicate.

Even though it may not be best to consider the relationship between volunteer and patient as a friendship, the strong bonds of connection that often arise between patient and volunteer are often motivated by concern, respect, shared values and trust. Relationships built on trust are necessary in order to speak about critical issues that are deeply ingrained in our humanity and spirituality like guilt, regret and forgiveness.

Sulmasy also believes such relationships are necessary for the spiritual care of patients:

The spiritual person is one who enters into a web of relationships in a spirit of gratitude and trust.... [Therefore], the spiritual doctor or nurse or

other health care professional is one who enters into relationships of trust with patients: inviting trust, behaving in a trustworthy manner regardless of whether or not that trust is reciprocated, and trusting in the basic goodness of a world of healing relationships. This takes great faith. It is risky.... It takes a lot of humility to trust. (*The Healer's Calling* 31)

According to Sulmasy, then, spiritual care and healing entails relationship, but not just any type of relationship. It is a connection that requires trust, humility, patience, risk and even comfort with uncertainty (ibid.). If we believe that speaking about issues like guilt or shame, or forgiveness also requires a relationship of trust (see discussions above), then one of the relationships that can play an important role with spiritual concerns is the volunteer.

However, the focus group responses, and some of the survey results, indicated a reluctance to address difficult discussions, especially those that may have touched on guilt and forgiveness, among volunteers who indicated they often formed friendships with patients (or were considered friends). Perhaps this reticence was due *to the existence* of a trusting relationship that evolved, a relationship in which the patient knew the volunteer would do no harm, and would offer acceptance and care no matter what was said or shared. If this was the case, then the volunteer was potentially a part of the healing process already, allowing a person to express regret or shame, which would then allow for deeper reflection or action regarding broken relationships. On the other hand, it could also be the case that the trusting relationships that evolved would have allowed for more significant conversations between patient and volunteer, had the volunteer received the training necessary to offer appropriate responses and care.

Boundaries. No matter how the bond between volunteer and patient is viewed, it is

important that limits and boundaries be recognized in order for the relationship to benefit the patient. To put it simply, spiritual care in any form requires the provider to “follow the client and stay out of trouble.” Put another way, boundaries are necessary for following the basic tenants of medical ethics and patient care, to do no harm and to do the best possible good for the patient. However, attention to boundaries is especially important for providing spiritual care, because “observing boundaries shows a healthy recognition of the purpose of the relationship and...avoids building walls.... [In fact], respect for boundaries...allows for compassionate presence in the healing encounter” (Puchalski “Ethical Concerns and Boundaries” 805-806). Therefore, an awareness of potential boundary issues is essential for training the volunteer, especially regarding spiritual issues. At RVH, one of the seven training sessions is dedicated to boundary issues and confidentiality. Even so, a brief treatment of these topics will be considered, especially since they are critical to potential conversations regarding guilt, shame and forgiveness.

Important in this discussion is the recognition of the relationship issues described above, namely that “hospice palliative care volunteers walk a fine line between being a patient’s/family’s friend and being a part of the professional care giving team” (Claxton-Oldfield, Gibbon and Schmidt-Chamberlain 429). Part of the potential difficulty with boundaries and other aspects of the patient/volunteer relationship is, again, how one defines the relationship as well as clarity about the role of the volunteer. Though the volunteer is a part of the care team, their role is unique and not always easy to define, perhaps even for patients. That is, as intimated in the quote above, patients and volunteers may see the volunteer as working more independently than the professional clinician – as both part of the team, yet recognized differently than other team members. This was evident in several key informant interviews and in some of the focus

group responses, especially from the volunteer who believed the patient revealed more to the volunteer than the professionals regarding personal or spiritual issues. She thought this was true due to the difference between the role and function of the clinician or chaplain, who she perceived to be beholden to the organizations (or care team) they represented, and the volunteer, who could be more independent, open and thus become a friend (see quote 52). Whether this is an accurate description of what the patient feels or believes is not certain, but it does highlight the potential for confused boundaries and roles regarding the patient/volunteer relationship.

One of the ways of dealing with this potential conflict would be to directly address the dual role of the volunteer, which may be seen as similar to that of the nurse or physician who provide medical care, but who also are involved in the spiritual care of the patient. However, the dual role is potentially more complicated for the volunteer since they frequently spend more time with the patient and family than other individual team members, and do often enjoy a relationship with the patient that is of a different kind than the one between patient and professional staff. Also, in contrast to professional staff, there are no formal ethical rules or structures of accountability that exist for the volunteer and may serve as a guide for suitable behavior. As a result, there is a greater possibility for confusing roles, over identifying with the patient, being too involved in helping the patient and family, and allowing “friendship” to affect the quality of care, especially spiritual care. Therefore, training and nuanced discussion of the volunteer role, patient/volunteer relationships, and what it means to be a member of a care team is vital.

There are many other boundary issues that can be discussed. For example, Claxton-Oldfield, Gibbon and Schmidt-Chamberlain conducted a study that identified twenty-seven behaviors that could be considered boundary issues, ranging from accepting money or gifts from

a patient, to offering advice about medical or spiritual issues, to sharing personal/intimate information regarding a volunteer's dealing with the death of a loved one. They also reported issues involving patient's communication or lack of communication with family members, conflicts of interest and observations of possible compromised care (431). Other potential boundary issues, especially regarding spiritual care, include volunteer self-disclosure regarding beliefs, feelings or experiences; openness to, or dismissing the patient's religious beliefs or experiences; and proselytizing (Robinson, Thiel and Meyer; Puchalski "Ethical Concerns and Boundaries").

Claxton-Oldfield, Gibbon and Schmidt-Chamberlain report an approach to boundaries shared by Porterfield at a NHPCO conference that is helpful, especially for training. Porterfield "distinguished between 'dotted lines' (i.e., things to be aware of), 'curbs' (i.e., things to stop and think twice about), and 'guardrails' (things to avoid)" (430). Regarding spiritual care, proselytizing is definitely an inappropriate behavior and is to be avoided in conversations with hospice patients, as is dismissing patient religious beliefs (Claxton-Oldfield, MacDonald and Claxton-Oldfield; Claxton-Oldfield, Gibbon and Schmidt-Chamberlain; Puchalski et al.; Puchalski "Ethical Concerns and Boundaries;" Robinson, Thiel and Meyer). Possible "curbs" involve the extent volunteers share personal information with the patient, and thus lessening the focus on the patient and their concerns. "Things to think about" may involve how and when a volunteer shares experiences pertinent to conversations about spirituality or end-of-life.

Other helpful instruction regarding boundary issues is present in literature, though most deal with the relationship between the patient and professional staff members. However, these insights can be helpful regarding the volunteer/patient relationship as well. For example, Robinson, Thiel, and Meyer offer help regarding negotiating self-disclosure issues by

challenging the caregiver to focus on “sharing context, not content.” Instead of disclosing details of a personal story the volunteer could use aspects of their own experience (or story) to formulate appropriate questions that help the patient think about and clarify their own issues (25).

Sulmasy also points to critical distinctions regarding the dual role. As a doctor and former Franciscan Friar, he was well aware of the potential confusion of roles between medical care and pastoral care. Both areas are critically important for the patient, but it is essential to reflect on what one can and cannot provide. Sulmasy understood that he was present as a “co-participant in the patient’s religious expression.... Not [as someone who] presided over that religious expression” (68, see discussion 67-68).

RVH volunteers are sensitive to the need to be clear about roles, to the extent that they are reticent to be helpful regarding pastoral care and spiritual healing, or are unaware of how conversations and relationships already touch on spiritual matters. Although the volunteers know they are not to initiate “opening the window” to possible conversation regarding religious and spiritual issues, it is important to reflect on what needs be done when the window is opened. Knowledge of, and attention to, boundaries and boundary issues can actually enhance the volunteer encounter with the patient, even helping to ease fears, reticence and distancing that may occur when such matters arise (Puchalski “Ethical Concerns and Boundaries”).

Confidentiality. Confidentiality is a specific boundary concern that is important for the volunteer/patient relationship and is already a focus of training for the RVH volunteer. Regarding spiritual issues, it is just as critical for volunteers to be protective of information the patient shares, as it is to protect other patient health information. When there is a sign of spiritual distress or concern expressed by the patient, or even when they express personal beliefs, it is not permissible to share such information with family or friends of the patient (unless the

patient has authorized the volunteer to do so), clergy, other visitors, other patients or the public. In some rare instances it may not be appropriate to share information with hospice staff. However, since the volunteer is part of the care team, it is important to share pertinent information in an appropriate way with staff, and only with those that need to know such information. In fact, confidentiality is not about keeping secrets or withholding information. It is intended to provide guidelines regarding who needs to know, what they need to know and when they need to know pertinent information necessary for care. Typically, concerns are shared through the volunteer coordinator or chaplain, depending on the protocol for the particular hospice.

Authority. Finally, an important issue already mentioned earlier is authority. In connection with spiritual concerns, especially guilt and forgiveness, it is essential to understand where authority resides for the patient. First and foremost, the volunteer “gets” their authority to discuss such issues from the patient, and only from the patient. Once the patient has invited the volunteer into conversations about spiritual and religious matters, it is also critical to keep in mind that different sources of/for authority inform belief and practice for the patient, including how a patient believes a remedy or avenue of healing is possible. Sacred texts or tradition may provide the basis for authority in a person’s life, meaning that patients may look to scripture or church tradition for answers or direction regarding matters of ultimate concern. The Eucharist, or a penitential prayer or rite may be central to their understanding regarding guilt and forgiveness. The patient may also invest authority in a representative of the church, or family member, or a trusted friend. For example, a Roman Catholic patient may need a priest to provide the necessary counsel and ritual regarding guilt and forgiveness. For the patient without affiliation, or even for some who are Protestant, the volunteer or another trusted person may be

able offer counsel, pray with the patient, or accompany them as they work out their need for forgiveness. In other cases, the pastor or faith community is the source of authority regarding guilt, shame, forgiveness and reconciliation. In fact, in many instances, it is the clergy who have knowledge and expertise regarding the liturgical and sacramental aspects of a patient's tradition that hold such power. In these circumstances, the volunteer may accompany or participate, if invited, being clear to acknowledge and respect the patient's need (Thiel 26 September 2014; Director of Pastoral Care 9 July 2013; Sulmasy *The Healer's Calling*). In short, it is important to understand how authority works in a patient's life in order to provide and integrate the most helpful sources for spiritual health and healing.

The cognitive apprenticeship has been given extensive attention in this work because it is foundational for other features of volunteer training to be a spiritual care generalist. The discussion above includes and suggests practical and formative aspects of the apprenticeship as well, such as the need for listening skills, issues regarding self-disclosure, or being empathetic and non-judgmental. Even so, it is important to discuss skills and identity issues that are vital to nurture and cultivate as the volunteer trains to be a spiritual generalist or spiritual care volunteer.

Practical apprenticeship: What skills do they need to have? There are a number of practices that are possible for the volunteer to engage in when caring for a hospice patient. Some of these involve everyday activities that are helpful or alleviate stress on the patient and family, like feeding the patient, helping to prepare a meal or engaging in some activity the patient enjoys. However, there are other practices that are critical to spiritual care, especially when the concerns touch on serious issues like guilt and forgiveness.

COMMUNICATION. One of the most important of these "practices" is communication. As

Planalp and Trost observe, “communication can be a route to finding meaning in death and to making and deepening connections with the living; at the same time, it can be a route to avoiding the reality of death and to losing opportunities to relate to others” (224). In other words, attentiveness to good communication skills provides a better opportunity for the patient to tell their story, reach a deeper level of sharing and honesty, seek appropriate response from someone they trust, and do this in an atmosphere of acceptance and care. Poor communication skills, or fear of what may be communicated, may actually be harmful to the spiritual wellbeing of a patient. Therefore, it is essential for the volunteer to be aware of and learn communication strategies that may impact the patient’s ability to share deeper issues like guilt, or convey a need to heal a broken relationship, or a need to seek forgiveness or some other resolution. These skills are especially important since the volunteer is often a person trusted and considered a friend by the patient, and may be privy to patients’ feelings and thoughts that other hospice staff and family may not encounter. The volunteer also needs to be comfortable with such conversations as well as the potential that what the patient communicates will likely venture into difficult and painful areas.

There are many skills related to communication with the patient, a subject that is addressed in training for RVH Volunteers. However, it is important to stress a number of strategies and ideas essential for the volunteer to keep in mind, especially when conversations turn toward more serious matters. First of all, it is important for the volunteer to listen well, which requires more than simply hearing the story or concern. Listening is being attentive with head and heart, engaging the patient in person-to-person encounter that lets the patient know their story or concern has truly been heard and understood. In fact, deep, engaged listening “is an act of love” and hospitality (Isay 1). It lets the patient know that their lives do indeed matter.

There are ways to listen well, which include methods that are both verbal and non-verbal. Some of these are well known techniques, like keeping eye contact, leaning in slightly to the patient, and avoiding closed posture. Others methods can be described as reflective listening, or active listening. When a person is listening “actively” the conversation remains on the patient, which means the volunteer is careful to avoid overtaking or directing the conversation, or offering too much in the way of self-disclosure. Reflective listening involves appropriate questions, both in kind (e.g., open ended) and number, in order to allow the patient to expand their story or explore their concern more deeply. It may also involve the volunteer paraphrasing or reflecting back what the patient has said, to make sure the patient has been understood. These are important ways of approaching the conversation, especially if the volunteer wants to be clear about a story or statement that possibly arises from feelings of guilt or regret, or to properly discern whether the patient is simply sharing a story as a way to connect or to seek validation. Active, compassionate listening also involves empathy, sincere interest, respect for the patient’s viewpoint, and being comfortable with silence. It avoids giving advice, judging inappropriately, anxious behavior, interrupting, or prodding the patient. Although the RVH volunteers are trained to provide a positive upbeat presence, such an approach should not inhibit or prevent the patient from expressing and talking about difficult matters like guilt and shame. In other words, being upbeat to a fault may communicate to the patient that the volunteer is unwilling to accept or receive a patient’s pain, or talk about struggles or wounds in a way that is helpful and healing (see Worthington 23-30; HealthCare Chaplaincy 20-30; Tutu and Tutu, Brown).

Another important aspect of communication, especially when dealing with sensitive issues like guilt and forgiveness, is the ability to offer appropriate response. Offering appropriate response is closely related to active or reflective listening, and is a way to allow the conversation

to move to a meaningful, reflective place. There are no handbooks that give exact instructions for particular issues, but there are a variety of resources that are helpful (e.g., Puchalski “Spiritual Stages of Dying;” HealthCare Chaplaincy; Tutu and Tutu; Carson and Koenig). Good responses allow the volunteer to reflect back content and meaning in ways that help the patient know they have been understood and which allow for further conversation. When dealing with issues like guilt, shame and forgiveness, there are responses that are inappropriate, like dismissing the patient’s feelings, giving specific direction or advice, expressing a judgmental attitude, or suggesting a remedy by proselytizing or attempting to “save” the patient. Even saying something like, “you did what you had to do” may be an attempt to be comforting, but may miss the point of a deep-seated grief or feeling of guilt.

Good communication practice is essential not only with the patient, but also with the hospice care team. Several authors suggest that the unique position and relationship the volunteer has with the patient allows them access to significant concerns and information. However, the information may be useless if the needs of the patient are not communicated effectively and appropriately (Claxton-Oldfield, MacDonald and Claxton-Oldfield; Worthington; Planalp and Trost). Therefore, it is helpful to learn how best, and when, to communicate information to the volunteer coordinator, chaplain or to the hospice care team.

EMOTIONAL COMFORT. Before a volunteer ventures into issues touching on spiritual concerns, it is critical for them to discern their comfort level with the variety of emotions that accompany spiritual distress, like anger, sadness, resentment and, of course, guilt. Dealing with these emotions is not easy, and requires a depth of care and self-awareness that allows the volunteer to be with the patient in their distress without showing undue discomfort or resistance. It also requires a sense of acceptance, empathy and compassion that will give the patient safe

space to offer their concerns. Some of the ways of conveying empathy and safety are, again, non-verbal, like keeping eye contact instead of averting one's eyes, leaning in instead of shying away, an appropriate touch of the hand, or a simple nod of concern. Consistent presence, reflective listening and other skills are also critical. However, addressing one's own attitudes and feelings is necessary so that the volunteer does not react in inappropriate ways, or work out their own issues in the midst of significant conversation with the patient. In other words, it is important for the volunteer who is a spiritual care generalist to develop skills that allow them to monitor and have awareness of their own feelings in the midst of offering spiritual care.

CONNECTION. Besides communication and emotional comfort, there are other skills that are helpful to develop. The capacity to “make a connection” is one such practice. Regardless of what conversations may or may not take place, RVH volunteers consider this an essential skill, since those connections help to build rapport, empathy and trust. The volunteer at RVH has a “tool box” he or she can use with various items that help initiate connection with the patient, which include printed material, pictures, or other items that may spark conversation. There are various techniques that can also be used such as attentiveness to items of interest in the patient's home or room. This “technique” is especially important regarding clues to the importance religion or spirituality. As Sulmasy reports, “sometimes patients...surround themselves with religious symbols and the like. I no longer ignore the open Bible or the Koran or the rosary beads or the Shabbat candles at the bedside” (*The Healer's Calling* 66). Although the volunteer needs to be cautious entering into religious conversations, it would be insensitive, perhaps even uncaring, to ignore obvious and vital signs of a patient's spiritual support and orientation. This is true for the tangible objects as well as comments made in the course of sharing. For example, when a patient wonders, “why God has not taken me,” the comment allows for entry into a

conversation that may reveal hidden concerns that touch on issues of guilt and regret or some other spiritual concern. However a patient's faith may be revealed, it is important for the volunteer to be capable of entering and negotiating encounters that uncover spiritual wellbeing or distress. It is also important to recognize and understand that connection and communication, and the building of trust, takes time.

RITUAL. Another skill important for the volunteer involves ritual, which could also be considered an item the volunteer "needs to know." Rituals not only help us deal with the chaos of death, but also are helpful for healing (Kushner "Religious Resources for Healing;" Tutu and Tutu; Carson and Koenig). Rituals are typically steeped in the liturgical and sacramental traditions of faith communities. However, they can also involve a practice the patient has invested with religious or spiritual meaning. Perhaps lighting a candle for prayer, singing a particular hymn, saying the rosary, or reading sacred texts daily may be "rituals" practiced by patients to help them cope with their circumstances. Rituals, both common and personal, may be crucial for those dealing with spiritual pain and distress, or issues like guilt and shame. The Lord's Prayer, for example, can help a patient focus on forgiveness in pretty profound ways. Daily devotions can help a patient explore their faith, opening them to deeper issues and the need to talk about what arises. Although the volunteer is not required to participate in the ritual important to a patient, it is vital to be aware of their ritual practices and engage with them if invited. Or it may be the case that the volunteer and patient will establish a ritual between them, like prayer each visit, that may lead to more significant conversations. One RVH volunteer indicated she regularly prayed with patients using the rosary, and brought along several versions of the Bible since many patients asked her to read scripture, especially Psalm 23. Such involvement allowed for sharing on a deeper, more spiritual level (Volunteer Key Informant No.

3 23 July 2013).

CONVEYING HOPE. If one of the important needs of the patient is retaining or holding on to hope in the midst of dying, then a crucial practice for the volunteer is to be an agent of hope. Thiel and Harris put it succinctly, “Hope happens in relationships. [Caregivers] are in unique positions to help bear our patients’ pain and dread through acts of empathetic witness, attentive listening and our continued presence and care” (235). Therefore, the practice of nurturing hope involves other “skills” mentioned already – listening well and truly hearing the patients’ stories, cultivating empathy, and offering tangible signs of care. It also involves something necessary for any kind of relational care - presence. In one of the focus group sessions the participants expressed that building trust and relationship required consistent presence. Keeping the promise to come back again and again was essential to their work as volunteers and the relationships that developed with patients (RVH Volunteers 1 April 2014).

To be an agent of hope also involves taking time to reflect on, and be aware of, sources for hope, cultivating and nurturing hopefulness within, and striving to be realistic (Thiel and Harris 235; O’Connor 139). If the volunteer is not able to be realistic, then a false sense of hope could be communicated. It is also difficult to be an agent of hope when hope is not a part of the volunteer’s spirit or outlook. Engaging in practices that cultivate hopefulness, then, involves nurturing truthfulness, an honest appraisal of circumstances and outcomes, and a faith in one’s relationship to God or something greater than oneself. Developing these practices and awareness allow the volunteer a chance to deal more effectively with issues like guilt and forgiveness, matters that strongly impact a patient’s feelings and sense of hope (Tutu and Tutu; Thiel and Harris; Puchalski “Spiritual Stages of Dying”).

CULTURAL AWARENESS. Although the vast majority of patients served by Ridge Valley

Hospice are somewhat homogeneous regarding racial, cultural and religious backgrounds, it is critical that the volunteer begin to develop greater cultural sensitivity. Culture not only influences attitudes about health care, death, spirituality, guilt and forgiveness, but also how a person may communicate, process information and form relationships (Carson and Koenig; Puchalski *A Time for Listening and Caring*; HealthCare Chaplaincy). Although an exploration of possible cultural influences is beyond the scope of this project, it is important that Ridge Valley Hospice and its volunteers be exposed to resources and training in order to reflect on, and be sensitive to, cultural differences and their own cultural assumptions. This is especially important if the volunteer is to be a part of spiritual care for the patient and is also critical when dealing with feelings and attitudes regarding guilt and forgiveness. For example, a number of patients served by RVH are members of the United Church of Christ (UCC), a mainline protestant denomination prevalent in the area. UCC patients may have varying views of guilt and forgiveness depending on their family of origin, the importance of religion and faith personally, neighborhoods where they grew up, and even the location and culture of the church or churches that most influenced their attitudes and values. Therefore, having some sensitivity regarding cultural differences and the various cultures and religious backgrounds of populations in the immediate area (Pennsylvania Dutch, Mennonite/Anabaptist, Reformed/UCC, Lutheran, Ukrainian Catholic, Italian Catholic, etc.) could prove invaluable to the person providing spiritual care. Training in cultural sensitivity will also become more necessary as demographics begin to shift and change.

TAKING A STEP BACK. The last “skill” to be mentioned involves a practice that is also critical in many aspects of life, the ability to take a step back. Although it is important to be conscientious as a volunteer caring for a patient, it is also valuable to develop a capacity to have

critical distance. Doing so will allow for reflection on a current or past relationship with a patient, constructive evaluation of care, and the chance to make changes that will benefit patients and the volunteer's relationship with them. Taking a step back to reflect and integrate experience is also helpful as a way to learn valuable lessons from previous encounters with patients, hospice team members, clergy and other volunteers. One volunteer shared that she takes such opportunities after a patient she is caring for dies, or even after particular visits. This allows her to learn from mistakes and successes as well as to acknowledge she has done the best she was able to do. These learnings and insights also help her to forgive herself when needed and make changes regarding patient care in the future (Volunteer Key Informant No. 1 15 July 2013). Her approach could be an incredibly valuable resource for her and other volunteers, especially when helping patients deal with guilt and forgiveness.

Normative apprenticeship: What kind of person does the volunteer need to be? There are certain attitudes and ways of being that are beneficial, and even necessary, to provide valuable spiritual care for the patient. This is especially true when dealing with sensitive matters that may be weighty or carry deep significance. A number of the qualities helpful for the volunteer to be a spiritual care generalist have been articulated in the discussion thus far. Essential for providing quality spiritual care are character traits like empathy, hopefulness, compassion, and trustworthiness, being non-judgmental and refraining from trying to "fix" the problem or make it go away (Tutu and Tutu; Sulmasy *The Healer's Calling*; Puchalski "Spiritual Stages of Dying;" Thiel and Harris). As articulated above, a volunteer also needs to be someone who can listen well, and who understands the ministry of presence. As the Director of Pastoral Care emphasized:

People know when the other person is there or not and presence is...valuable to a person who may not need much more.... So showing up and hanging in there, and allowing the other person to touch us, to get to us, well, volunteering and being in ministry is all about relationship.... *and the healing is in the relationship.* The techniques that you use and the disciplines that you use all help to frame and reframe and hold in a safe way the relationship, and that's where the healing is. (9 July 2013)

SELF AWARENESS/SELF-CARE. Self awareness and knowing the need for self care are also critical for the volunteer who is to offer spiritual care to the patient and be comfortable with issues like guilt and forgiveness. An awareness of one's own feelings about death, transcendence, purpose, meaning, God, faith, brokenness, guilt, forgiveness and other spiritual issues are fundamental for the volunteer who offers care that touch on these matters (Kushner "Religious Resources for Healing;" Puchalski "Ethical Concerns and Boundaries;" Carson and Koenig; Nouwen). Such reflection offers a foundation for conversation and helps the volunteer to recognize and keep distinct their own feelings and those of the patient. At the same time, deliberation regarding these issues also allows the volunteer to be compassionate and understanding, knowing that we are all broken in some way and in need of healing. Without reflecting on God or forgiveness or other issues of spiritual importance, the volunteer may unconsciously focus on their own struggles or lack of understanding; or they may lack sufficient compassion or empathy. Instead, the caregiver has a responsibility, if they want to be fully present to the patient, to "prepare through reflection" on matters like these (Puchalski "Ethical Concerns and Boundaries").

Self-care, and spiritual practice are also important "ways of being" for the volunteer who

offers care for the spirit of patients they see (Cornette; Puchalski “Spiritual Care;” Sulmasy *The Healer’s Calling*). Self-care may mean taking a break from hospice for a time, or engaging in regular exercise, or engaging in activities that are meaningful and bring joy. Spiritual practice can also be a form of self-care, though such practices are best described as ways to deepen connection with God, the significant or sacred. Sulmasy alerts us to another purpose of spiritual practice, especially regarding spiritual care: “in the silence of prayer, the health care professional’s own pain will surface. In silence before God, there is no place to hide” (*The Healer’s Calling* 49). The same can be true of the volunteer who practices a spiritual discipline. Connecting in prayer to pain and brokenness allows the volunteer or caregiver to be in touch with their own spiritual resources, find ways to healing, and identify ways to be compassionate to self. Making one’s own spiritual journey in this way also opens the volunteer to a greater potential for compassion, hearing the patient’s story in a different way, identifying spiritual issues more clearly, and having conversations about avenues of healing with the patient. Spiritual practice and self-care, like self-awareness, also helps prevent the volunteer from “projecting [their] ideas, [their] needs, and [their] pain into another’s story” (Cornette 153).

VULNERABILITY. Dealing with the spiritual concerns of another on any level can be difficult and will definitely touch our own wounds (Nouwen; Puchalski “Spiritual Care;” Sulmasy *The Healer’s Calling*). As the Director of Pastoral Care put it, “people are going to get to you, and that’s good, but it’s going to cost you.... We go into this knowing that, but knowing it does not minimize it or the pain. Just listening and being present to someone in pain will get to you” (9 July 2013). If this is the case, then spiritual care of the patient will require a level of vulnerability for both patient and volunteer. To tell one’s story is already to take risk in a relationship. The willingness to hear the story, to continue the conversation and reflect what was

heard and understood, also means to move into uncertain territory. Openness to what the encounter may cost emotionally, intellectually and spiritually can be a venture into the most vulnerable parts of our selves. Such engagement can touch on long held hurts and pain, but can also lead to profound healing. Yet, as Brown asserts, “vulnerability is at the core, the heart, the center of meaningful human experiences” (12). Healthy vulnerability is about seeking connection. It is understanding that life is about defeat and victory, loss and healing, hurt and growth, and yet engaging in life and relationship. It is not about helplessness, being defenseless or exploiting weakness. In fact, “the level to which we protect ourselves from being vulnerable is a measure of our fear and disconnection” (Brown 2). So, to be vulnerable in healthy ways, which allows for deeper connection, requires a tremendous amount of discipline, training, sensitivity and care. It also requires of the volunteer a keen sense of limits, a strong sense of self-understanding and perceptive insight into what the patient needs.

Of course, providing this level of spiritual care for the patient may not be for everyone, and not every volunteer will be able to deal with the hurt and intensity, or offer spiritual care in a way that is helpful. However, even the awareness that one is not able, willing or ready to offer such care is beneficial to the patient, since such an awareness allows the volunteer to be honest with themselves and the patient about limits to the relationship. Even for the volunteer who is willing to deal with deeper spiritual concerns, more education and training is necessary, though not enough. Self-care and awareness, being vulnerable in healthy ways, spiritual practice and cultivating one’s spiritual life are also critical, if not essential, “ways of being” that allow one to offer vital spiritual care (Nouwen; Sulmasy *The Healer’s Calling*; Cornette; Puchalski “Spiritual Care”).

EXPERIENCE. The data and literature also highlight experience as an important trait for

volunteers providing quality spiritual care. Most of the RVH volunteers who were key informants or in the focus group had experience with hospice before volunteering since they had loved ones or friends on hospice. This was reflective of hospice volunteers nationally as well (RVH Volunteers 25 March 2014; Claxton-Oldfield and Claxton-Oldfield). Through such experience the volunteer was able to observe how health care professionals, chaplains and other volunteers provided care. They gained insight into various kinds of care as well as what quality care looked like, and were often inspired by these experiences to become volunteers themselves.

However, experience seen from a different point of view is especially critical when considering the kind of person a spiritual care volunteer needs to be. Planalp and Trost indicate that, “experienced volunteers may be more at ease with death talk than new volunteers are, and older volunteers may have had more experience with death in their own lives and so may be more willing to engage” (225). This insight is likely to be true regarding many aspects of spiritual care, especially regarding guilt and forgiveness. Although more experienced or older volunteers may be lacking the knowledge and training to engage these issues on a deeper level, their encounters with patients or others who exhibited or spoke about spiritual distress or feelings of guilt has already provided them with a chance to develop a sensitivity to these concerns. Perhaps the reason why the focus group did not reach the depth I had hoped in conversations about guilt and forgiveness was connected to this perspective regarding experience. Only one member of the group had over five years experience and another had four years with RVH. The rest of the volunteers in the focus group had one and a half years of experience or less. Many of the volunteers with little experience also mentioned that a number of patients they had visited were not communicative, due to dementia or being near death and unresponsive, which limited exposure to possible conversations regarding spiritual matters. However, the volunteers in the

focus group and among key informants with more experience simply had more encounters with communicative patients, and thus more stories to tell and experiences to share that touched on feelings of guilt, regret and forgiveness. It is also somewhat intuitive that the more experience a volunteer may have, the more comfortable they may feel engaging in conversation and spiritual care with the patient, especially if more training were made available. In fact, this is what the focus group began to assert throughout our sessions and especially as we came near the end of our time together (22 April 2014).

Finally, a story told in *Educating Clergy* is instructive regarding the normative apprenticeship of volunteers. Professor Henry Ferry, a history teacher at Howard University Divinity School, said he “opened his class on church history by introducing his students to the ‘Four H’s’” (xii), which he believed would be helpful for them as they studied church history, but also for their work as pastors and in ministry. The Four H’s were honesty, humility, humor and hope. His instruction to his students is also important for volunteers or anyone providing spiritual care. That is, such care requires honesty of thought and approach, even when honesty brings one close to difficult and problematic issues; humility in the face of the stories and hurts that are shared and the realization that the deepest healing is beyond the volunteer’s abilities or capacity to care; that humor is often a way to truth, but also used to counter the heaviness of issues like guilt and shame; and hope, the faith that healing and transformation can indeed occur, even at the end-of-life (xii-xiii).

Chapter VI

Next Steps and Implications

The research and analysis in this project has been focused on the volunteer's role in providing quality spiritual care for the patient. Hospice volunteers already provide a number of services regarding direct care for the patient including regular visitation, helping with patient needs, engaging in conversations about family, everyday matters, or even serious issues, and being invited to share in religious ritual and practice, like saying prayers or reading the Bible. The volunteer at RVH, above all, is encouraged to offer a compassionate, upbeat and nonjudgmental presence, to be a trusted companion with the hospice patient as they transition toward death.

It has been argued in this work that the hospice volunteer may be in a unique position to experience opportune moments, times when the patient wishes to share issues that touch on spiritual matters, like struggles with guilt or a need for forgiveness. The previous chapter has addressed this possibility and highlighted specific components for training volunteers to be spiritual generalists. Such training has been proposed so spiritual care for the patient could be enhanced, or at least assisted in some significant way by the volunteer. Of course, challenges were also considered, especially regarding the nature of the patient/volunteer relationship and boundary issues, as well as matters like the need for self-awareness on part of the volunteer, familiarity with the spiritual assessment, effective communication techniques and the connection of the volunteer with the hospice care team.

In light of these issues, it is important to make a number of suggestions how the components of the "apprenticeship" can be integrated into the life and practice of the volunteer as they serve the patients in their care. The following pages will offer general direction and recommend a few resources that would be helpful for this task.

This chapter will also address implications this research may have for the church as well as suggestions for further investigation and study. These matters are important considerations not only for the spiritual care and wellbeing of those in hospice, but for the spiritual care of others who suffer with illness and disease, or who struggle with critical spiritual issues like guilt and forgiveness.

ESTABLISHING AND ENCOURAGING VOLUNTEER APPRENTICESHIP

In order to become spiritual care generalists, volunteers will require education and training beyond the basic instruction at Ridge Valley Hospice. Since experience matters as well, it is suggested that volunteers have at least two years experience in direct patient care before they are approved to provide the most basic level of care as spiritual care generalists (see Rumbold's levels of care, 81-82 above). Education and training to be a generalist should begin for volunteers who have a year or more experience, except in cases where the volunteer worked in areas like nursing, social work, counseling, or as clergy.

There are a variety of methods and resources that can be helpful in this endeavor to train volunteers to be spiritual care generalists. Some educational methods and reflective practices are more suitable to particular aspects of the training, though approaches may intersect two, or all three of the "apprenticeships" discussed. To offer some clarity for direction, a brief description of suggested methods and practices will be proposed regarding the three apprenticeships and how they serve the overall training.

Cognitive. Education and training in this area is primarily didactic in approach, designed to assist the volunteer in acquiring pertinent information discussed above as helpful or necessary to

become a spiritual care generalist. Workshops, individual classes, or an intensive course of study similar to the basic training would be helpful to introduce and explore areas like: the spiritual assessment; distinguishing spiritual and religious; working with patients who may be “spiritual, but not religious; dealing with guilt, regret, shame and forgiveness; friendship/relationship and boundaries, and their relation to spiritual care; self-awareness and self-care; religious rituals; and cultural sensitivity. These modes of education can be offered quarterly for those in training, included on an occasional or regular basis in monthly presentations already offered the volunteers at RVH, offered once a week over an intensive period of six or seven weeks, or made available through online resources.

There are a number of resources that could be helpful for instruction and learning. For example, the Director of Pastoral care offers a course in basic pastoral skills for those in churches or other organizations that may need such knowledge to inform skills. This course covers areas like the pastoral conversation, grief and loss, listening and response, and diagnosis and planning. It is taught through lectures and discussion/reflection on the material and experiences. Puchalski et al. suggest several educational avenues, including resources through The George Washington Institute for Spirituality and Health. Some educational tools from the Institute are available online and include articles, power point presentations, multimedia guides, lectures/talks and links to other websites focused on spirituality and health (*The GW Institute for Spirituality and Health*). There are numerous resources as well to aide the volunteer with cultural and religious awareness and sensitivity which include sections in training manuals, articles and books that focus on spiritual care (see HealthCare Chaplaincy 66-89; Carson and Koenig 189-205; Tiew et al.; Puchalski *A Time for Listening and Caring* 131-225; Doka and Morgan 19-129) as well as resources like *How to Be a Perfect Stranger: The Essential Religious*

Etiquette Handbook (Matlins and Magida). Although these materials do not give specific instruction regarding issues like shame and guilt, they are certainly helpful in other areas of needed training and provide a context for beliefs and attitudes regarding guilt and forgiveness. It would be helpful for the volunteer (and staff alike) to have resources like these in an accessible library in the RVH offices.

Practical. There are a number of educational avenues to pursue to develop the skills necessary to become a spiritual care generalist. The focus group, or small group model could be helpful to introduce and explore material on a cognitive level, but also as a way to discuss cases that arise in volunteers' experiences with patients. For example, there were several stories shared by the RVH volunteers in the focus group that could have been presented as a verbatim and used to discuss and practice possible directions the patient/volunteer conversation could have taken. The WWII veteran, the woman who shared about her treatment of her children, or the gentleman struggling with what to believe (see focus group results, chapter 4) were all stories that could have touched on issues of guilt and forgiveness. Simply focusing on listening and response regarding these situations in a volunteer focus group would allow for development of skills through instruction, practice and insights from the leader and participants. Role-play, another form of practical instruction and training would be especially helpful for the small group model, and could be combined with other educational methods as well.

One of the critical aspects of volunteer skills training regards communication; not only between the volunteer and patient, but also between the volunteer and hospice care team. Again, workshops, classes, and focus groups that utilize role-play are essential for honing these skills. There are a number of resources helpful in this endeavor as well, including online sites/webinars

useful for class sessions, or accessed individually by the volunteers. For example, HealthCare Chaplaincy has produced a training manual that provides helpful instruction regarding listening and responding skills (HealthCare Chaplaincy 20-40). Another excellent option is the webinars available through the Schwartz Center in Boston. Some webinars at this site address communication strategies for dealing with challenging conversations and building trust with patients (“Educational Programs”). There are other educational opportunities through the NHPCO website as well (*National Hospice and Palliative Care Organization*).

One issue that needs attention in this apprenticeship model is how best to deal with supervision and feedback. Helpful in thinking about this problem is the practical training clergy receive, which includes a number of models that allow the seminarian and pastor ample time for “practice, reflection and adjustment” (Mellott). One of those models that may be helpful for training volunteers to be spiritual care generalists is Clinical Pastoral Education. Others have used the CPE model to train palliative care and healthcare staff to be spiritual generalists, although the practice is somewhat innovative and new, and not yet widely used (Robinson, Thiel and Meyer; Thiel 26 September 2014). Of course, the expense and time to engage in a CPE program may be prohibitive for most volunteers and beyond the budgetary constraints of RVH and other hospice organizations that provide care. However, developing a program that includes a combination of instruction, patient care, supervision, peer group work and reflection would be ideal. Supervision in this model could be provided by the hospice chaplain and volunteer coordinator, or could possibly include other volunteer supervisors who are clergy, chaplains, or directors of pastoral care. It would be preferable for the supervisors to be CPE trained, and desirable for supervisors to have completed four units of CPE and be board certified. Unfortunately, many hospice care organizations do not have access to such highly trained

chaplains, so some accommodation may need to be made to include those who are highly skilled, have supervisory experience, and some CPE training. Whether a CPE model is used or not, some supervision and chance for feedback is necessary for the volunteer to integrate and improve skills.

Another aspect of communication involves interaction with the staff. At present, RVH volunteers complete field notes after each visit and submit them to the volunteer coordinator. There is typically little or no direct communication between the volunteer and other staff, including the chaplain. One suggestion recommended in the literature is to allow more interaction between volunteer and staff, especially in hospice care team meetings when patients a particular volunteer is visiting are being discussed. This would allow for the volunteer to offer information they may know that other team members do not, but would also provide an opportunity for education and critical lessons for the volunteer regarding the care of patients (Claxton-Oldfield, MacDonald and Claxton-Oldfield). Another suggestion to enhance communication and learning is to include volunteers and staff together in training (Wittenberg-Lyles, Schneider and Oliver). At the least, staff could be involved in small groups, discussion or other classes for volunteers as resource persons or to share their own stories and experiences regarding spiritual issues, especially those that touch on guilt and forgiveness (there is already staff involvement in basic training for volunteers).

Normative. Education and training for this aspect of the apprenticeship includes individual practices and reading as well as a significant communal piece. Several manuscripts already mentioned in the discussion about the normative apprenticeship could be helpful for the volunteer as they develop the character, attitudes and ways of being valuable to the spiritual care

generalist. Especially useful is the *Book of Forgiveness*, which provides educational material and insight regarding forgiveness, but also offers practices to integrate learning and how to forgive (e.g., journaling, creating artwork, meditation and reflecting on one's own story). Henri Nouwen's classic, *The Wounded Healer* and Brené Brown's works covering her research into shame and vulnerability are also instructive and challenging.

It would also be useful for those training to be spiritual care specialists to take some form of the Myers-Briggs Type Indicator test, which indicates personality types and cognitive styles. It would be helpful for the volunteer to know their personality type in order to discover and reflect on how they process information, interact with others, perceive the world and make judgments and decisions. Although the test is not perfect, it often gives fairly accurate information that would allow the volunteer to gain some measure of self-awareness, which is critical for helping another (i.e., patients) with significant issues. Mary Martha Thiel asserts that most people in pastoral care are "NF's" (intuitive/feeling) on the Myers-Briggs scale, and that their personality and way of processing make it easier for them to hear issues of guilt and regret imbedded in a patient's story. On the other hand, "ST's" (sensing/thinking) do not hear the story in the same way and find it more difficult to discern feelings of guilt or needs for forgiveness, especially if there is limited information (Thiel 26 September 2014). Whether or not Thiel is correct about the number of a particular personality type in pastoral care, her insights regarding Myers-Briggs personality types are important to keep in mind for training, self-understanding and recognition of strengths and weaknesses for the vital work of spiritual care.

One of the essential elements of work as a volunteer in general, and as a spiritual care generalist in particular, is the need for self-care and practices that nourish the soul. Practicing self-care can help to ease stress, prevent compassion fatigue and avoid burnout. Self-care

includes a measure of awareness of limitations and when one needs to step away for a time to re-energize or reflect, or to simply take a break. To be a hospice volunteer, to care for the dying, is very rewarding. Yet, it can be difficult work and requires that a person be grounded and know how to nurture the needed inner resources to care for another. Kushner reminds us that our inner resources to do this work come from the source of our own spiritual well: “if what you are giving patients is your love and your strength, you’re going to run dry by Wednesday afternoon at the latest. If what you’re giving them is God’s love and God’s strength, for which you are a channel, then you don’t have to worry about running dry because there is more where that came from” (“Religious Resources for Healing” 14).

There are other way to nurture the soul and to find the strength and resilience to offer spiritual care to those at the end of life. Prayer disciplines, journaling, quiet meditation and other spiritual practices can be helpful ways to nourish the spirit, connect with the source of life greater than ourselves, and find the appropriate distance that may be needed on occasion. It is also important to find time to grieve and space to acknowledge pain and other feelings that accompany the death of a patient, especially when a deep relationship of trust was developed with them. Self-care also includes physical exercise, developing rituals of release or letting go, as well as rituals of memory and celebration, attending the funeral of a patient, and interacting with and sharing with other volunteers or staff who are part of the hospice team (Jones; Helsel).

In fact, community is critical for self-care and self-awareness, for healing and nourishment, and is a source of strength and support. Nouwen once wrote that, “A Christian community is ... a healing community not because wounds are cured and pains are alleviated, but because wounds and pains become openings or occasions for a new vision. Mutual confession becomes a mutual deepening of hope, and sharing weakness becomes a reminder to

one and all of the coming strength” (94). Though speaking about Christian community, Nouwen’s words are just as valid for the community that can exist between hospice volunteers and team members, and provides insight that touches on the potential healing power of the volunteer/patient relationship.

IMPLICATIONS FOR THE CHURCH

Similar to work with patients in hospice and palliative care, the life of the church involves ministry and care to those wounded in body and spirit due to sickness, life limiting illness or trauma. Some may be receiving medical attention, while others have had to make unexpected transitions to retirement communities or a facility offering a high level of nursing care. There are sometimes those who may be dying. Hopefully, in light of these realities, members of the church can be nurtured and educated in the art of compassionate care.

Just as for hospice volunteers, Paul’s account related at the beginning Chapter 5 is instructional for those in the church who wish to offer nurture and comfort to those who are hurting or dying. Interestingly, his anecdote also parallels a well-known Biblical narrative, the story of the Good Samaritan (Luke 10: 25-37). When paired together, these stories communicate powerful lessons and imagery grounded in real life experience and Christian faith. Like several in the Biblical narrative, Paul could have passed by on the other side and ignored the woman in need and her companion’s plea for help. Instead, Paul acted as neighbor to a woman he did not know. Even though there was no cure for the dying woman, he bound the wounds of loneliness with a ministry of presence and care. Indeed, Paul’s actions exemplified some of the best insights of the story of the Good Samaritan, which inspire the effort of all who take the risk to be neighbor, offering relationship and care for those in need.

However, for both the hospice volunteer and the church member, there may be times they feel “passing on the other side” is preferable to saying the wrong thing, or sitting in awkward silence, or simply not knowing what to say. I have also witnessed, in many a hospital room or home, times when a church member or others visiting have said the wrong thing or acted in ways less than gentle and caring, or focused the attention on themselves. Therefore, offering educational opportunities for church members informed by scripture and coupled with insights in this research could be beneficial for church communities. Although the training described above may not be practical or possible for most members in the church, there is knowledge and skills mentioned that would be appropriate for instruction during Sunday classes or weekend workshops that could enhance visitation and compassionate care. Exposure to instruction regarding listening and response, spiritual vs. religious, friendship/relationship and boundaries, and other areas would be helpful for many church members. Furthermore, at the church I serve, a number of congregants are taking the basic pastoral skills course offered by the Director of Pastoral Care, while others are hoping to do the same in the future. The Shepherds committee at the church is encouraging and supporting this ministry as a way to assist the pastors of the church and enhance congregational care through a Pastoral Care Team. Further education and training similar to that suggested for the spiritual care generalist could be a vital and useful addition as pastoral care volunteers in the church gain more experience and cope with challenging moments and issues with members and friends.

Even if the material offered in this work is not used for training or greater awareness for church members making pastoral visits, there are plenty of lessons that can be culled from the information presented. Exploring guilt, shame, forgiveness and reconciliation would be a valuable avenue to pursue through sermons, classes and workshops. For example, offering a

class or workshop that helped members or participants view guilt in a healthy way, or that made use of the book by Tutu and Tutu on forgiveness, could provide a needed opportunity for reflection, deepened spirituality, action and healing. A focus on vulnerability and relationship through the lens of Brené Brown's work, or as presented in many an article for this paper, could also challenge and deepen one's connection to God and others.

Finally, giving attention to friendship/relationship to others, community, boundaries and confidentiality are all worthy areas of study and instruction. The church is indeed an odd and wonderful community of people that includes deep friendships, those seen as spiritual friends, some not known and others that are tolerated and loved as Jesus has called us to love. However, negotiating these various relationships, being mindful of boundaries, and being careful with issues of confidentiality are extremely important issues in the church. In fact, a breakdown in relationships, boundaries and confidentiality have wounded and broken community in many a congregation. Therefore, some attention to these critical aspects of life as mentioned in this discussion could offer valuable perspective and practice.

SUGGESTIONS FOR FURTHER RESEARCH

There are numerous research opportunities that can be suggested regarding various aspects of this thesis. First, of all, it would be helpful to develop and evaluate a pilot program for volunteers at Ridge Valley Hospice using the suggestions noted in this work, as well as input from staff at RVH (primarily volunteer coordinator and chaplain) and the Director of Pastoral Care. The pilot study would involve five to ten volunteers, preferably with five years or more experience, over a two to three year period.

Another avenue of research could be to explore patients' (and patient family's) thoughts

and feelings regarding the role of the volunteer. Although it was not possible for this study, insight from those being cared for would be helpful in determining the need for volunteers to be spiritual care generalists. Investigating whether patients would welcome conversations with volunteers regarding spiritual matters like guilt and forgiveness would also be a focus. Such a study would further examine the volunteer/patient relationship and whether friendship is a help or hindrance to deeper, more serious conversations.

It would also be important to do research regarding guilt and regret, and the need for forgiveness among family and caregivers of hospice patients. With much focus on the needs of the patient, the family member's concerns may be given too little attention. Although there may be bereavement care available after a loved one's death, sufficient consideration regarding these sensitive and complicated issues may be lacking or deficient. Just as hospice care is oriented toward compassionate care for patients facing the end of life, it is also concerned with care for the family and caregivers. Therefore, research regarding feelings of guilt, and how to seek forgiveness when the loved one is no longer there, could be invaluable.

As noted earlier, nurses and social workers at RVH also provide spiritual care to patients, or are involved in conversations related to spiritual matters. However, according to the Volunteer Coordinator, there is little training regarding spirituality and spiritual care. A similar study to that outlined in this thesis could be performed with the RVH staff through key informant interviews, surveys and focus groups. Some of this work is already being done nationally and much of the literature regarding spiritual care and the palliative care (or hospice care) team involves research with nurses, physicians, psychologists and social workers. In fact, a number of articles used for this work were authored, or co-authored by physicians and nurses who work in the palliative care or end of life care. In light of the research available regarding hospice care

staff and their need to be trained in the area of spiritual care, it would be valuable to include Ridge Valley Hospice staff in the pilot program already mentioned above. In fact, training could occur with a mixed group of staff and volunteers, with appropriate information pertinent to staff/patient relations offered separately.

Hospice care is a form of palliative care, which is “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering” (“Palliative Care”). Hospice is focused on patients with a particular diagnosis who will no longer receive curative treatment. Much of the funding for hospice comes from Medicare and Medicaid. Palliative care programs are more broadly conceived and serve patients with a terminal or life-altering illness. They are funded by other forms of insurance, are less regulated by the government, and can include curative treatment. However, palliative care in general also focuses on holistic care provided by a palliative care team similar in makeup to that required for hospice care. The spiritual health of the patient is just as critical to the goals and purpose of palliative care. Much of the research happening today in reference to spirituality and spiritual care is being conducted in palliative care settings, or from the vantage point of palliative care philosophy and practice. This research is and has been critical for informing the more specialized area of hospice care. Since this is the case, research regarding spiritual care could be conducted for the palliative care program at Ridge Valley Hospital as well, or as a way to begin integrating the spiritual component more deeply into the organization’s practice.

It is also evident that more work needs to be done in reference to religious and cultural diversity, and the impact of that diversity on conversations regarding guilt, shame, forgiveness and reconciliation. Although Tutu and Tutu suggest that a person using their book on forgiveness need not be a person of faith, their perspective is unmistakably Christian. In fact,

much of the conversation about guilt and forgiveness in the literature consulted for this study was immersed in religious understandings, and primarily from Christian, Jewish and Buddhist perspectives. Although these understandings and approaches may still be extremely important for most patients in hospice care now and in the future, there will likely be a time when the cultural shifts will necessitate language and understandings that diverge from current religious conceptions. At the least, more consideration and research needs to be conducted regarding those who are atheist, or those who self identify as *nones*. This research will necessarily involve exploring further the language used to convey feelings like guilt and forgiveness.

Cultural diversity is also a special issue to investigate, especially with regard to hospice care. The NHPCO estimates that in 2014, 76.0% of hospice patients nationally were white/Caucasian; 13.1% Multiracial or other; 7.6% Black/African American; 3.1% Asian, Hawaiian, Other Pacific Islander; and 0.3% American Indian or Alaskan Native. 7.1% of these patients identified as Latino or Hispanic (NHPCO's Facts and Figures 7). These figures indicate slight shifts toward greater racial and ethnic diversity compared to previous years and suggest diverse cultural heritage as well. Health care in general, and spiritual care in particular, is definitely affected by a patient's cultural context. For example, African-Americans are more likely to distrust the healthcare system due to societal and institutional racism as well as historical abuses. This distrust often leads to medical decisions that may involve more aggressive treatment and medical care that prolongs life that, consequently, affects spiritual care. In addition, many African American patients who are Christian may view spiritual issues in a way consistent with immersion in African American churches, which emphasize God's power over life (rather than a physicians or other caregivers power), as well as different attitudes regarding guilt and forgiveness (see excellent discussion in Kagawa-Singer and Blackhall; G.

Taylor). Cultural understandings, then, are already important and worthy of further research, and will become more critical in the future as national demographics change.

Another possibility for exploration involves the intersection of this work with research involving other populations that may need special attention regarding spiritual care at the end of life. For example, dealing with guilt, shame and forgiveness may be of critical importance for hospice patients who are incarcerated. As with hospital or hospice patients in general, inmates are a highly vulnerable and protected group when doing research, and will require extensive protections. Nonetheless, it might be helpful to examine whether volunteers in prison hospice programs should be trained to assist prison chaplains with spiritual care, especially regarding issues of guilt and forgiveness.

Similarly, another subject of interest that could benefit from more extensive research along the lines of this study is the care of war veterans who are receiving hospice or palliative care. Moral injury is a special area of research involving veterans that is deeply connected to issues of guilt and regret. Rutledge gives insight into this issue in one of her sermons. She tells of a young man weighed down with guilt over actions he committed in wartime. The response of many to his struggles, that “he did what he had to do,” was not good enough for the veteran. Rutledge then proclaims,

That young man was crying out for someone to say something that would acknowledge the pain of war, the death of non-combatants, the fury and folly of it all. *He doesn't want easy forgiveness.* He doesn't want civilians who never served in the armed forces to tell him that he shouldn't feel bad. He already knows that war is hell; he doesn't need anyone to say it. He knows that “things” do not always work out for the best. He is groping for something beyond that.

(“God and ‘Things’” my emphasis)

Although every veteran who becomes a patient receiving palliative or hospice care may not need to work through struggles like these, it is evident that more and more war veterans are dealing with issues of guilt and moral injury. Consequently, there may be a greater need in the future for those especially trained to provide specialized spiritual care in these instances. Further, many who are facing the end of life, whether veterans or not, are groping for something beyond the pat answer, or the response that fails to touch one’s deepest need. Such research, then, could have wider application and benefit.

Finally, research with dementia patients is a new and growing area, especially regarding communication and memory. Studies could also be done that deal with “ritual memory” (e.g., a dementia patient mouthing The Lord’s Prayer), human connection, release, and ways of providing spiritual care. Although there are programs emerging to more deeply connect with dementia patients, evidenced based research is lacking, especially regarding the patient’s spiritual health (Planalp and Trost).

LIMITATIONS OF THE STUDY

Some limitations of this study have been implied or made explicit in the previous section and elsewhere. Nonetheless, some will be mentioned again in order to clearly address deficiencies and delineate possible areas for improvement or expansion.

Ample literature and previous research indicates that patients often reach out to health care providers at the opportune time when a need arises, or when a struggle occurs. Therefore, it was appropriate that this study regarding the role of the hospice volunteer, and their relationship with the patient, focused primarily on research and exploration *with the volunteer*. The

volunteer's perspective and opinion is certainly valuable and necessary to take into account concerning the many issues discussed in this thesis. However, it would have been best to consult hospice patients and their families served by RVH about their perceptions, needs, expectations and hopes regarding the hospice volunteer and their relationship with them.

The demographics of hospice patients served by RVH can also be seen as limiting, especially in relation to the contribution this research can make to the larger hospice community. The patients served by RVH are typically white/Caucasian, are often native to the area and state, and are overwhelmingly Christian or steeped in Christian culture and upbringing. However, the demographic figures released by the NHPCO (related in the previous section) indicate that the racial and ethnic makeup of the RVH population may not be that different than the majority of hospice patients in the United States. Although there is no detailed information regarding religious affiliation among hospice patients nationally, it is plausible that the cultural heritage of a significant percentage of hospice patients nationally reflects a Christian heritage and culture. In light of this information, the results and research conducted at Ridge Valley Hospice may be of some help to the general hospice community. It is clear, though, that further research taking into account cultural and religious diversity is needed, especially if the hospice movement desires to serve and offer support to an increasingly diverse population.

It is also true that many of the patients served by hospice are non-responsive, or suffer from illnesses or medical conditions that limit their ability to communicate. Several focus group members shared that a significant number of the patients they had seen were unresponsive, had severe dementia, or were close to death. Therefore, the chance to have any significant conversation was limited or simply not possible. In these instances, training will likely be unhelpful, especially if the percentage of unresponsive patients increase. Further, if hospice is

viewed only as care provided in the last days or weeks of a person's life, then the potential benefits and depth of care provided by hospice will be lost, including enhanced spiritual care. In spite of these limitations, it is important that the volunteer, or a small group of volunteers, be trained for those opportune times a patient needs their attention and ability to offer spiritual care.

Other limitations involve specific aspects of the research and its implications. One issue has to do with the number of focus groups. Typically, two or more focus groups are needed in order for research the research to be generalizable. Although triangulation of the data was helpful to offer credence to the reliability of the data, being able to conduct research with two or three focus groups would have been helpful.

Another issue had to do with the focus group process and the leadership provided by the researcher. In the first and third focus group sessions, the volunteers were given ample freedom to influence the direction and depth of the conversation. In the second focus group session, though, there were several moments where the researcher spoke and explained too much, which possibly affected group participation and response. However, follow up and probing questions as well as follow up in the next focus group session moderated the effects of these missteps.

Other problems have to do with the suggestions for education and training. First, the training to be a spiritual generalist will take time and adequate commitment on the part of the volunteer. It may be that what is being suggested is too ambitious, or not feasible in light of resources (budget and staff), volunteer interest or patient need. Also, in terms of staff, a board certified chaplain overseeing the training might be necessary rather than simply preferred.

Finally, professional hospice staff and health care providers must follow the ethical standards of their profession and the organizations they serve. As paid staff, hospice care workers also have a structure of accountability that influences the quality and consistency of

care. Volunteers, on the other hand, have no stated ethical standards, though they do sign documentation to ensure that confidentiality standards are followed. Also, there are inadequate means of accountability, a deficiency that should be addressed if volunteers are to be involved in higher levels of spiritual care.

CONCLUSION

The number of persons who will need palliative or hospice care in the future will inevitably rise as the population continues to age, and especially as baby boomers grow older. If this is the case, then it is important to prepare for the needs of the influx of patients who will need the holistic care provided by hospice and palliative care organizations. Yet, it is also critical to meet the needs of those who are already receiving hospice or palliative care, or will need these services in the immediate future.

Essential to hospice and palliative care is a holistic care model that addresses the physical, emotional, cognitive, social and spiritual needs of the patient. This study has focused on the spiritual needs of hospice patients, particularly those at Ridge Valley Hospice, and the role of the volunteer in offering spiritual care. Central to the research has been the question “who should be involved in helping the patient address spiritual concerns, especially feelings of guilt, regret and the need for forgiveness?” Also, is the chaplain or spiritual care provider the only qualified person that can offer the depth of assistance necessary with these issues, or is it possible for the volunteer to have some minor or significant role?

Although a definitive answer to these questions has not been given (alas, more research needs to be done!), the study with the volunteers at Ridge Valley Hospice has suggested that a greater role by volunteers in the spiritual care of patients is not only possible, but may be crucial

for the spiritual wellbeing of the patient. The opportune time for spiritual care, as argued, does not wait for the chaplain, clergy or spiritual counselor. Many times conversations and stories that touch on deeply human matters like guilt, shame and forgiveness arise in the midst of simple everyday interaction, as well as in relationships of trust. What is evident is that volunteers are indeed trusted and often counted as friends by patients, and this relationship, within the context of appropriate boundaries and adequate training, can be the context for needed healing and spiritual care. This research has concluded that volunteers can fill such a role, and that training to be spiritual care generalist is a necessary and vital part of offering quality care.

Ridge Valley Hospice has nearly one hundred volunteers, with approximately 70-75 providing direct patient care. It is likely that a number of volunteers will be satisfied with the basic training already received in areas of communication, boundaries, confidentiality, death and dying issues and basic matters regarding spirituality. In other words, not all volunteers may wish to become spiritual generalists, or have the personality and temperament to do such work. Further, many hospice patients do not need a spiritual care generalist to provide care since they are unresponsive due to their illness, have advanced stages of dementia, are opposed to spiritual care or conversations about significant matters, or are in a good place spiritually. Therefore, again, it may not be necessary or even practical to train all volunteers to be spiritual care generalists. Depending on the size and census of a particular hospice agency, only a few or handful of spiritual care volunteers may be needed.

However, for those with the desire, interest and disposition, it is important to receive appropriate training and instruction to become a spiritual care generalist. The discussion in this work has offered a fairly comprehensive examination of the multi-faceted aspects of the volunteer apprenticeship needed to be a generalist, though it is not an exhaustive treatment.

Nonetheless, it is an attempt to describe a number of recommended practices and areas of instruction for Ridge Valley Hospice if they choose to train volunteers, or a select number of volunteers, to assist with the noble work of spiritual care for the patient. Such training is especially critical if volunteers are to respond appropriately to matters of deep concern for the dying patient, matters like guilt and forgiveness. These issues are not trivial subjects, but are matters that touch deeply our spirit and humanity. Consequently, they are issues of great significance that may affect the patient's ability to find healing and face death with dignity, assurance and spiritual wellbeing. If the ultimate purpose of care for the hospice patient includes facing these matters and concerns, then the volunteer apprenticeship may well be necessary and vital to that end.

APPENDIX A

The questions below tell us about your hospice volunteer experiences. Select the response that most closely matches your feelings or experiences in light of interactions with patients and caregivers (unless otherwise noted).

In your role as a hospice volunteer, how often do you....

	Never	Rarely	Sometimes	Most or all of the time
1. discuss diseases or medical treatments?	(A)	(B)	(C)	(D)
2. discuss coping with a terminal illness?	(A)	(B)	(C)	(D)
3. discuss family relationships?	(A)	(B)	(C)	(D)
4. discuss <i>broken</i> relationships?	(A)	(B)	(C)	(D)
5. discuss feelings of guilt and regret?	(A)	(B)	(C)	(D)
6. discuss the burden of care on family members?	(A)	(B)	(C)	(D)
7. discuss God or faith?	(A)	(B)	(C)	(D)
8. discuss legal concerns or personal finances? (i.e. power of attorney or will)?	(A)	(B)	(C)	(D)
9. discuss topics that the patient does not speak with family members about?	(A)	(B)	(C)	(D)
10. share personal stories to let patients know that you empathize with their struggles?	(A)	(B)	(C)	(D)
11. develop a personal friendship with the patient or family members?	(A)	(B)	(C)	(D)
12. pray, read from the Bible, or participate in a spiritual activity with patients?	(A)	(B)	(C)	(D)
13. focus on things that the patient is grateful for?	(A)	(B)	(C)	(D)
14. act as a compassionate listener?	(A)	(B)	(C)	(D)
15. offer suggestions to fix current problems?	(A)	(B)	(C)	(D)
16. avoid difficult, personal subjects?	(A)	(B)	(C)	(D)
17. provide an upbeat presence?	(A)	(B)	(C)	(D)
18. refer patients to the hospice chaplain?	(A)	(B)	(C)	(D)
19. document the patient's struggles in hospice notes?	(A)	(B)	(C)	(D)
20. verbally communicate the patient's struggles to the volunteer coordinator or other hospice staff?	(A)	(B)	(C)	(D)

How comfortable are you in discussing the following topics with patients or caregivers?

	I would never discuss this topic	I would like training, so I will feel more comfortable	I feel somewhat comfortable	I feel very comfortable
21. Communication between family members	(A)	(B)	(C)	(D)
22. Broken relationships	(A)	(B)	(C)	(D)
23. God and faith	(A)	(B)	(C)	(D)
24. Forgiveness	(A)	(B)	(C)	(D)
25. Spiritual care	(A)	(B)	(C)	(D)
26. Personal acceptance (accepting oneself, warts and all)	(A)	(B)	(C)	(D)
27. Caregiver burnout	(A)	(B)	(C)	(D)

Are there additional comments you would like to make (especially regarding items/questions above)?

Thank you for your time and effort.

APPENDIX B

Confidential

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Study: The role of hospice volunteers in helping patients and caregivers deal with guilt and regret and other spiritual issues.

Louis E. Kuykendall, Jr. (Butch)
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Volunteer Chaplain, Ridge Valley Hospice
c/o Community United Church of Christ
address listed in original
address listed in original
Telephone listed in original
bkuykendall@lancasterseminary.edu

You are being asked to take part in a research study under the direction of the Rev. Louis E. Kuykendall, Jr. (Butch). Approximately eight people will participate in this study.

Purpose:

The purpose of this research is (1) to discover to what extent hospice volunteers encounter and/or recognize issues of guilt and regret (and related spiritual issues) in their care for the patient or caregiver; (2) to determine the level of comfort of the volunteer in dealing with these issues; and (3) to define best practices.

Duration and Location:

The focus group(s) will meet twice for an hour and a half for each session. A third meeting will be held to validate findings from previous meetings. All meetings will be held in a private, distraction free area at Community United Church of Christ or a suitable location at Ridge Valley Hospital.

Procedure:

At the start of each focus group participants will be reminded to protect patient confidentiality and not to use the names of patients they have cared for. Focus groups will explore volunteers' experiences with and responses to issues of guilt and regret (and related spiritual issues) among hospice patients and caregivers.

Inclusion and Exclusion Criteria:

Focus group participants must be a volunteer with Ridge Valley Hospice that (a) have at least three months experience, and (b) are currently designated as being on active status. Participants who serve as a volunteer hospice chaplain will be excluded.

Risks and Discomforts:

There are no risks associated with focus group participation. There may be an inconvenience

due to the time required to participate or psychological or social discomfort caused by questions or discussions regarding participant's experiences with hospice patients and caregivers.

Right to Refuse or Withdraw from the Study:

Participation in this study is voluntary. You may refuse to participate, or may discontinue your participation at any time. There is no penalty for refusal to participate or withdraw from the study. Participation is not required to serve as a volunteer with Ridge Valley Hospice.

Use of Research Results:

The data obtained in this study will be used by the investigator in completing a research project. Results will be conveyed through a report to the Ridge Valley Hospice Volunteer/Bereavement Coordinator and may be used for a final thesis for the Doctor of Ministry degree, conference presentations, publications and teaching purposes. Your responses are confidential. No participant will be named in any report or publication of the study or its results.

Benefits and Payment:

There are no benefits for participation to study participants. Ridge Valley Hospice and society will gain insights into best practices for hospice patients and their caregivers.

Confidentiality:

The focus group sessions will be recorded via a digital recorder and stored on a password-protected computer. In order to ensure confidentiality, all data will be recorded such that an individual's responses cannot be matched directly to the participant.

Institutional Review Board Approval:

This research study has been approved by the Ridge Valley Hospital Institutional Review Board (IRB) for the Protection of Human Subjects in Research. If you believe that there is an infringement upon your rights as a participant in this research you may contact the IRB Secretary at Ridge Valley Hospital, Telephone ***-***-****.

Participant's Agreement

I have read the information provided above and voluntarily agree to participate in this research study. If I have any questions or concerns that arise in connection with my participation in this study, I should contact the IRB Chairperson through the IRB Secretary at Ridge Valley Hospital (***-***-****).

If you agree to participate, please sign your name below. Signing your name below indicates that you have read and understand the contents of this Consent Form.

Participant's Signature

Date

Investigator's Signature

Date

APPENDIX C

Questions/Script for Ridge Valley Hospice Volunteer Focus Group

Session 1

Please tell us your first name, how long you have been a volunteer with Ridge Valley Hospice, and what led you to become a hospice volunteer. [probe- what attracted them to volunteer, expectations of role]

Many hospice volunteers report developing a friendship with the patient (or caregiver). Can you describe the role of friendship to me? What are the advantages of being a friend to the patient? What are the limitations?

Without giving patient names, can you describe a situation that you found particularly challenging as a hospice volunteer?

I want to know more about feelings of guilt and regret at the end of life. Can you give me some circumstances or reasons why patients experience feelings of guilt or regret? Have you ever encountered these issues in your role as a hospice volunteer? How did you deal with these issues? [probe for level of comfort. Probe for sense of guilt and regret in their own lives may affect or influence their care]

Session 2

In this session, I would like to know more about your interactions with patients about faith, God, and the afterlife. What types of spiritual activities or rituals do you engage in with the patient? [probe for patient responses to the activities] How do you feel about these activities?

What kinds of spiritual issues do you notice among patients? [probe- does the conversation remain on the surface; who leads the conversation- patient or volunteer?] How do you handle loss or struggles with faith? [probe again how they themselves have dealt with loss and struggles with faith]

Do caregivers share issues regarding faith with you? When this occurs, is your response different, or your comfort level different, than discussing such issues with patients?

Do you refer patients to the hospice chaplain? Why? Why not? [probe for the perceived role of the hospice chaplain vs. hospice volunteer]

APPENDIX D

In your role as a hospice volunteer, how often do you....

	Never (%)	Rarely (%)	Some- times (%)	Most or all of the time (%)
1. discuss diseases or medical treatments?	27.9	39.5	32.6	0.0
2. discuss coping with a terminal illness?	20.9	41.9	27.9	9.3
3. discuss family relationships?	4.7	18.6	48.8	27.9
4. discuss <i>broken</i> relationships?	37.2	37.2	25.6	0.0
5. discuss feelings of guilt and regret?	31.0	42.9	23.8	2.4
6. discuss the burden of care on family members?	14.3	35.7	42.9	7.1
7. discuss God or faith?	7.1	19.0	59.5	14.3
8. discuss legal concerns or personal finances? (i.e. power of attorney or will)?	66.7	31.0	2.4	0.0
9. discuss topics that the patient does not speak with family members about?	34.1	29.3	34.1	2.4
10. share personal stories to let patients know that you empathize with their struggles?	7.1	9.5	54.8	28.6
11. develop a personal friendship with the patient or family members?	4.8	19.0	33.3	42.9
12. pray, read from the Bible, or participate in a spiritual activity with patients?	7.0	34.9	39.5	18.6
13. focus on things that the patient is grateful for?	2.3	7.0	58.1	32.6
14. act as a compassionate listener?	0.0	2.3	4.7	93.0
15. offer suggestions to fix current problems?	14.3	33.3	47.6	4.8
16. avoid difficult, personal subjects?	19.0	40.5	23.8	16.7
17. provide an upbeat presence?	0.0	2.3	14.0	83.7
18. refer patients to the hospice chaplain?	23.3	48.8	20.9	7.0
19. document the patient's struggles in hospice notes?	2.4	2.4	11.9	83.3
20. verbally communicate the patient's struggles to the volunteer coordinator or other hospice staff?	4.7	9.3	34.9	51.2

How comfortable are you in discussing the following topics with patients or caregivers?

	I would never discuss this topic (%)	I would like training, so I will feel more comfortable (%)	I feel somewhat comfortable (%)	I feel very comfortable (%)
21. Communication between family members	4.8	26.2	31.0	38.1
22. Broken relationships	7.3	26.8	43.9	22.0
23. God and faith	0.0	22.0	22.0	56.1
24. Forgiveness	2.4	16.7	23.8	57.1
25. Spiritual care	2.4	19.5	22.0	56.1
26. Personal acceptance (accepting oneself, warts and all)	2.4	16.7	19.0	61.9
27. Caregiver burnout	4.9	22.0	19.5	53.7

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