

“The Priest as Clinician: A Case for Intentional and Informed Involvement of Parish Clergy with Clinical Teams Caring for Parishioners”

JOE KIMBELL DUNAGAN

Project under the direction of Professor Robert D. Hughes, III

A challenge for parish clergy is to minister to parishioners as they experience illnesses in such a way as to help transform the experience of being sick from one of objectification and isolation, to an experience that can be interpreted as part of their spiritual journeys. This thesis illustrates how barriers to spiritual care of parishioners during times of illness can be breached and parish priests can become full participants in the healthcare team. To be integral in the delivery of care, clergy must be intentional and informed.

Narratives of persons confronting illness while being objectified and isolated by the healthcare system are utilized to illustrate this thesis. These stories include early seventeenth century Anglican priest and metaphysical poet, John Donne; Sue Baier, who wrote about her experience of being paralyzed for weeks in a modern intensive care unit; the main character in Margaret Edson’s play about a Donne scholar with terminal cancer; and, stories adapted from the author’s ministry.

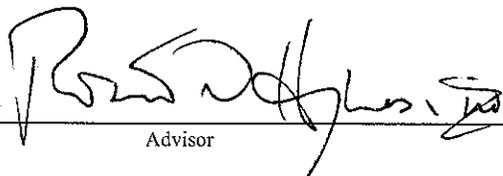
The divergent understanding of spirituality is problematic, but there is agreement among clergy and clinicians that spirituality understood in some fashion is important. This common ground can be an entry point for parish clergy who seek opportunities to interact with clinicians.

The *medicalization* of illness occurs when clinicians focus on treating the disease, i.e. curing or changing the course of the illness. This treatment is typically data driven, algorithmic and influenced by costs. With clergy involvement, all healthcare can be

more holistic. The clinical term *palliative* refers to treatment that aggressively manages physical, emotional, social and spiritual symptoms and which addresses the patient and family as a unit of care. A palliative approach to episodic, chronic and terminal illness that involves a patient's clergy and parish complements clinical interventions and may affect outcomes.

Anglican incarnational theology holds that God is with us in our suffering. The prayers of the Church include petitions for healing but there is no denial of death. The prayers for sanctification of suffering suggest that illness can be a part of our spiritual journeys. These theological and liturgical spiritual disciplines are suspect in clinical settings where spirituality is appreciated but not well defined and certainly not of primary importance to healthcare professionals. Parish clergy need not be daunted by the realities of the healthcare system or defeated by its clinical culture, language, social strata and rules. The key to becoming effective in clinical settings and integral to the care of sick parishioners is intentionality, information and focus, one soul at a time.

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The Priest as Clinician: A Case for Intentional and Informed Involvement of Parish Clergy with
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Joe Kimbell Dunagan.

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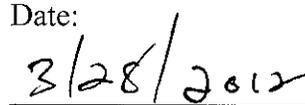
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Approved:

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Date:

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The Priest as Clinician: A Case for Intentional and Informed Involvement of Parish Clergy with Clinical Teams Caring for Parishioners

Introduction

The public debate about healthcare in America is a political debate about healthcare finance and delivery. For parish clergy, the challenge is to minister to parishioners as they experience illnesses in such a way as to help transform the experience of being sick from one of objectification and isolation, to an experience that can be interpreted as part of their spiritual journeys. An entire section of the Book of Common Prayer is devoted to *Ministration to the Sick*.¹ There are prayers for recovery from an illness, before an operation, and for strength and confidence in the face of illness. Most pertinent for parish clergy in clinical settings is the prayer for the sanctification of illness. This prayer asks that one's weakness might add strength to faith and seriousness to repentance.² The prayer reflects an understanding of the sanctification of an illness that comes through community and accepts that suffering is a part of life. Jesus joins human suffering. Prayers of the faithful do not make individual suffering disappear any more than the advent of Christ made suffering disappear from the human condition, even among the faithful. Rather, the ministry of Jesus transforms suffering. When in pastoral ministry the Church continues the joining with those who suffer as Christ does, healing occurs as wholeness is restored. Wholeness includes suffering.³ With intentionality and information, parochial clergy can become integral to the provision of healthcare and offer a transcendent dimension to the overall care of the sick. This transcendence is evident

¹ *The Book of Common Prayer and Administration of the Sacraments and Other Rites and Ceremonies of the Church Together with the Psalter or Psalms of David According to the Use of the Episcopal Church* (New York: Church Hymnal Corporation, 1979), 453-461.

² *The Book of Common Prayer*, 460.

³ David Smith, *Health and Medicine in the Anglican Tradition* (New York: Crossroad, 1968), 8.

when, as a result of pastoral intervention, parishioners no longer focus on, “Why is this happening to me?” Their question becomes, “How can I grow spiritually through this experience?”

A ministry of presence, rituals, and listening to their stories are important representations of community, transcendence, and narrative, all of which give meaning to life in the face of suffering and death. Priests and deacons who do not let their ministries become ancillary to the interventions of clinical caregivers can help sick parishioners remain connected to their faith community. From his deathbed, John Donne asked, “Why callest thou me from my calling? In the door of the grave, this sickbed, no Man shall hear me praise thee.”⁴ Donne’s sense of vocation gave a spiritual dimension to his suffering. His calling to the priesthood “intermingles with thoughts about the soul’s vocation and the final destiny.”⁵ The goal of the priest as clinician is to help parishioners discern how to live out their own vocation in times of sickness.

The barriers to spiritual formation during times of illness include the isolation and objectification of the sick. In Chapter 1, this objectification and isolation is voiced in first person accounts by three patients. John Donne, the seventeenth century Anglican priest and metaphysical poet, described in his *Devotions Upon Emergent Occasions* what he had believed was his deathbed experience after being misdiagnosed. Sue Baier is a survivor of a catastrophic episodic illness who wrote about her experience in a modern intensive care unit. And, Margaret Edson’s play, *Wit*, tells the story of the final days and death of a woman in a research hospital.

⁴ John Donne, *Devotions Upon Emergent Occasions*.

⁵ Frank N. Magil and Ian P. McGreal, eds., *Christian Spirituality: The Essential Guide to the Most Influential Spiritual Writings of the Christian Tradition* (San Francisco: Harper and Row, 1988), 280.

Chapter 2 addresses spirituality as the term is understood and used by parish clergy and by clinicians. The story of “Philip,” a patient with great unmet spiritual needs, illustrates the importance of addressing the spiritual needs of the sick. An exploration of literature about spirituality in clinical settings by clergy and clinicians reveals there is common ground. Both appreciate the importance of spirituality. This common ground of appreciation can serve as an entry point for parish priests and deacons to become integrally involved across the disjointed continuum of care and to elevate the spiritual care of individual patients to the higher ground of their own religious heritage and unique spiritual journey.

Palliative care is a holistic approach that aims to alleviate physical, emotional, social *and* spiritual symptoms. Cure and prolonging life are not goals of palliative care. In Chapter 3 “Gary’s” story illustrates how palliative care, in addition to curative and life prolonging treatments, would have benefited both patient and family. Parish clergy generally know sick parishioners and their families both over time and in their own familiar surroundings. With this knowledge of the family system and the patient’s values, along with access to information about the prognosis and diagnosis, clergy can effectively introduce a palliative approach well before an eventual end-of-life referral to hospice.

In Chapter 4, the case narratives of “Mike” and “Janie” are used to illustrate two important points. First, data driven decisions may not result in what is best for a particular individual. Second, when caring for the sick is a congregational mission, a parish working together can improve healthcare one soul at a time. Mike and Janie were both terminally ill. He wanted to continue aggressive treatment against the odds and

everyone's advice. Janie was more prepared to die than she was to live with the indignity and isolation of treatment. In both cases, the priest's involvement helped insure the right to self-determination and holistic or palliative care prior to the end of their lives. The sanctification of their illness is evident in the way their weakness added strength to their faith and, especially in Janie's case, seriousness to their repentance.

Chapter 1

Helping Parishioners Overcome Objectification and Isolation that Characterize the Medicalization of Illness

Improving end-of-life care and overcoming the medicalization of death has attracted much interest. This thesis argues that similar attentions should be given to improving care during any episodic or terminal illness by overcoming the *medicalization of illness* through the involvement of parish clergy as integral to the group caring for the sick. This group may include family members, personal care aides, physicians, nurses, chaplains, various therapists, social workers, friends or fellow parishioners, and clergy. For purposes of this discussion, those who make their living in any clinical setting, e.g. hospital, nursing home or physician's office, will be referred to as *clinicians*. Clergy will generally refer to parochial priests and deacons, not clinical chaplains. Of all these persons, a sick individual's priest is unique. The priest's livelihood is parish ministry but unlike clinicians the priest's livelihood is not impacted directly by a patient's choice of treatment options. Moreover, the priest is less likely to try to influence patients to make strictly data-driven decisions. Rather, the priest is more at home speaking of discernment. Finally, a parish priest is much more likely to be present with a sick parishioner from diagnosis to recovery or death than any clinician and is able to visit the sick in their homes as well as the variety of clinical settings in which they may be treated. Unlike family and friends, the priest, even though caring and loving, is personally involved but has a certain amount of emotional distance and objectivity. All these things have the potential to help overcome the medicalization of illness for parishioners.

Fowler describes how the contributions of philosophical theorists of developmental psychology have offered contemporary versions of *ordo salutis*, the path or steps to salvation, by providing reassurance that crises can be understood in developmental terms.⁶ The medicalization of illness prevents sick persons from seeing not only how this part of life can help persons developmentally but also how spiritual growth can result. Fowler sees adult development theorists as storytellers and mythmakers. A parish priest who is present and actively involved in the health crises of parishioners serves a critical and important role in helping the sick to see how their stories intersect with the Sacramental story. More than an intellectual or theoretical exercise, there is a transcendent quality to pastoral sacramental interventions. As development theorists “enable us to see that much of our dis-ease can be understood as ‘sickness unto new health’—a developmental transition—rather than ‘sickness unto death,’”⁷ a parish priest enables sick parishioners in his or her care to see this as sickness unto new life. This is not possible when patients’ unique experiences are replaced by diagnosis based plans of care with treatments based on symptom algorithms.

Death and taxes may still be the only certainties in life but with the advent of modern healthcare, we can be almost as certain of episodes in our lives when we will be patients. Unless death comes instantly as the result of a car crash or other such accident, or a catastrophic physical event such as an aneurism, we will experience the dehumanizing process of going from autonomous individual to an exposed and vulnerable patient. This objectification begins with diagnosis.

⁶ James W. Fowler, *Becoming Adult, Becoming Human: Adult Development and Christian Faith* (Jossey-Bass, 2000), 10-11.

⁷ Fowler, 11.

For Sue Baier the diagnosis was Guillain–Barré syndrome. Sue lived in suburban Houston, Texas. One morning she noticed some tingling in her feet and hands. Her physician assured her it would pass. The next day she had difficulty swallowing. She was admitted directly to an intensive care unit from the emergency center at a Houston hospital. “Bed Number Ten” became her home and her eponym for more than three months. Still able to sit up and talk, Sue was told by her first critical care nurse to remove all her clothes and jewelry. She pleaded to keep her wedding ring but was told she could not have any personal effects except a tooth brush. Her condition deteriorated quickly leaving her completely paralyzed. The only physical control she retained was the ability to blink. Baier described her first morning in bed number ten:

Fear surged through me as I tried to roll over onto my side. My body did not have enough strength. (A nurse) walked past the bed again so I summoned the courage to ask for help...The morning shift was arriving. With one nurse from the night shift, the new group made rounds, standing at the foot of each bed to be familiarized with that patient’s condition. When they came to my bed, I listened carefully.

“Probably Guillain–Barré,” she reported with passiveness that made me feel invisible—or dead. “Lumbar puncture scheduled for seven-thirty.” My heart pounded. The spinal tap! I forgot that was coming. Dear God, please help me.⁸

She was experiencing what happens when we become patients. She had gone from being Sue Baier to being *Bed Number Ten*. She had gone from active to passive, from autonomy to heteronomy. Eventually that was completely reversed when she presented her own case in grand rounds at Baylor College of Medicine. As a resident in Clinical Pastoral Education at one of the affiliated teaching hospitals, I was in the audience to hear her speak. She was a small woman who wore braces on her hands and feet as a result of muscle atrophy. I remember her taking a sip of water from a glass she

⁸Sue Baier with Mary Zimmeth Schomaker, *Bed Number Ten* (CRC Press, 1986), 20-21.

had to hold with both hands. Even with amplification her voice seemed little more than a whisper but, unlike her first morning in the hospital, everyone in the amphitheatre was focused on her, listening intently to every word she whispered.

Her illness would have certainly led to death without ventilation. She survived weeks of near total paralysis in an Intensive Care Unit. Throughout the ordeal she was able to feel pain, hear everything in her cubicle, and think. With the help of her husband's journal notes and a co-author she wrote a book about her overnight transformation from *Sue* to *Bed Number Ten*.

Even with all the dramatic life preserving advances in healthcare, the sudden objectification Baier described is not a new experience for the sick. John Donne's account of his illness, treatment and objectification in 1623 has much in common with Baer's. He described the onset of his illness: "This minute I was well, and am ill, this minute."⁹ Like Guillain-Barré syndrome, Spotted Fever's symptoms come on suddenly and without warning and leave the victim lucid but physically helpless. He wrote of his physician's fear in his presence and of his loneliness. "As *Sickness* is the greatest misery, so the greatest misery of sickness, is *solitude*; when the infectiousness of the disease deters them who should assist, from coming; even the *Physician* dares scarce come."¹⁰

John Donne was a seventeenth century Anglican priest and one of the foremost metaphysical poets.¹¹ His words about death and dying are well known. His legacy is the insight expressed through his *Devotions on Emergent Occasions* which includes his

⁹ John Stubbs, *John Donne: The Reformed Soul* (W. W. Norton & Company, 2006), 401.

¹⁰ Stubbs, 401.

¹¹ Geogfrey Rowell, Kenneth Stevenson and Rowan Williams, *Love's Redeeming Work: The Anglican Quest for Holiness* (Oxford University Press, 2003), 141.

most famous words, “Ask not for whom the bell tolls, it tolls for thee.”¹² In his poem he describes how all persons are connected existentially. What is less appreciated is Donne’s reflections on the objectification of being a patient and his own experience of the medicalization of illness.

Donne’s *Hymn to God, My God in My Sickness* expresses the objectification felt by patients then and now:

Since I am coming to that holy room,
Where, with thy choir of saints for evermore,
I shall be made thy music; as I come
I tune the instrument here at the door,
And what I must do then, think here before.

Whilst my physicians by their love are grown
Cosmographers, and I their map, who lie
Flat on this bed, that by them may be shown
That this is my south-west discovery,
Per fretum febris, by these straits to die,

I joy, that in these straits I see my west;
For, though their currents yield return to none,
What shall my west hurt me? As west and east
In all flat maps (and I am one) are one,
So death doth touch the resurrection.

Is the Pacific Sea my home? Or are
The eastern riches? Is Jerusalem?
Anyan, and Magellan, and Gibraltar,
All straits, and none but straits, are ways to them,
Whether where Japhet dwelt, or Cham, or Shem.

We think that Paradise and Calvary,
Christ's cross, and Adam's tree, stood in one place;
Look, Lord, and find both Adams met in me;
As the first Adam's sweat surrounds my face,
May the last Adam's blood my soul embrace.

So, in his purple wrapp'd, receive me, Lord;
By these his thorns, give me his other crown;
And as to others' souls I preach'd thy word,

¹² John Donne, *Devotions Upon Emergent Occasions: Meditation XVII*.

Be this my text, my sermon to mine own:
"Therefore that he may raise, the Lord throws down."¹³

His metaphor of the physicians as mapmakers and he the two dimensional object of their attention captures the evolving isolation of illness. As their passion increased their compassion decreased. It is not Donne they love but their map. Earlier he had written the opposite:

I am a little world made cunningly
Of Elements, and an Angelike Spright...¹⁴

Again, in an essay entitled *Microcosm*:

It is too little to call man a little world; except God, man is a diminutive to nothing. Man consists of more pieces, more parts, than the world; than the world doth, nay, than the world is. And if those pieces were extended, and stretched out in man as they are in the world, man would be the giant, and the world the dwarf; the world but the map, and the man the world.¹⁵

His illness and the experience of being a patient caused Donne to see himself no longer as an autonomous creature whose influence reduces the physical world to a map but as a creature helpless to influence the world. His fever is a strait through which he is passing to death. Donne is discovering through his experience of dying something of the meaning of life. The physicians who treated him as a cartographer would a map did what people often do to the sick. Donne believed he was dying, and in facing his own death he understood the connection we have with all humanity because of our mortality. He continued the geographical metaphor with what may be his best remembered lines:

¹³ John Donne, *Hymn to God, My God, in Sickness*.

¹⁴Geoffrey Rowell, Kenneth Stevenson and Rowan Williams, *Love's Redeeming Work: The Anglican Quest for Holiness* (New York: Oxford University Press), 2003.

¹⁵ Rowell, Stevenson and Williams, 148.

No man is an iland, intire of it selfe; every man is a peece of the Continent, a part of the maine; if a clod bee washed away by the Sea, Europe is the lesse, as well as if a Promontorie were, as well as if a Mannor of thy friends or of thine owne were; any mans death diminishes me, because I am involved in Mankinde; And therefore never send to know for whom the bell tolls; It tolls for thee.¹⁶

Because Donne was such a gifted and prolific writer, the experiences of sick persons who benefit from medical interventions but are also objectified by the medicalization of their illness is eloquently documented. Here it is worth noting that affluence and access to medical care may even exasperate it. Donne's influenced is evidenced by the fact that King James dispatched his personal physician to treat Donne.¹⁷ Having the resources to *do everything* can mean one's illness is even further medicalized with procedures and travel to the best known hospitals for treatment. As the fictional Professor Bearing observed, "I am not in isolation because I have cancer...(but) because I am being treated for cancer."¹⁸

Margaret Edson's play, *Wit* is the story of a Donne scholar named Vivian Bearing who finds herself hospitalized with Stage IV ("There is no stage five."¹⁹) metastatic ovarian cancer. Edson's metaphor for the objectification of illness and hospitalization is her character's experience of being read by her physicians as she had read seventeenth century existential poets. Early in the play, Professor Bearing is examined by an oncology fellow who happens to have been a student in her class on Donne. He has her on an examining table wearing nothing but a hospital gown with her feet in stirrups when

¹⁶ Donne, *Devotions Upon Emergent Occasions: Meditation XVII*.

¹⁷ Stubbs, 401.

¹⁸ Margaret Edson, *Wit* (Faber and Faber, 1993), 47.

¹⁹ Edson, 12.

he remembers there is a policy requiring the presence of a female during a pelvic exam. He leaves her in that predicament and rushes off to find a nurse. Alone, the patient recites Donne's Holy Sonnet X, "Death be not proud..." Eventually the research fellow returns with a nurse who chides him for leaving her alone. Until the examination begins there is an edge to the interaction between the patient and her former student. The nurse scolding him about his disrespectful treatment of her adds another element of humanity to the situation. But once the examination is in progress and the young physician feels the tumor, he completely forgets himself and swears.

Professor Bearing is as intellectually prepared for death as one could possibly be. In a monologue she says to herself, "I know all about life and death. I am, after all, a professor of seventeenth century poetry...specializing in the Holy Sonnets of John Donne...which explore mortality in greater depth than any body of work in the English language."²⁰ However, this is not a play about death and dying as much as about the experience of medicalization of the experience. The playwright drew on her own experiences working in an oncology unit, studying Donne, and caring for her brother who died of cancer, in telling this story.²¹ Her depiction of objectification is heard in Professor Bearing's observations during Grand Rounds:

Here, "Rounds" seems to signify darting *around* the main issue...which I suppose would be the struggle for life...*my* life...with heated discussions of side effects, other complaints, additional treatments.

...Full of subservience, hierarchy, gratuitous displays, sublimated rivalries—I feel right at home. It is just like a graduate seminar.

²⁰ Edson, 12.

²¹ Carol Cohen, *Margaret Edson's Wit: An Audience Guide* (Madison Repertory Theatre, 2001) <http://faculty.smu.edu/tmayo/witguide.htm> (accessed October 21, 2011).

With one important difference: in Grand Rounds, *they read me* like a book.
Once I did the teaching, now I am taught.²²

Baier, Donne and Edson tell their stories and vicariously tell the story of everyone who becomes a patient. It is a story of objectification caused not by the sickness but by the medical interventions that limit both autonomy and functionality. For Baier this objectification took the form of being identified as *Bed Number Ten*. Donne referred to himself as a map studied by his physician cosmographers. Edson's fictional Professor Bearing compared herself to a book being read and discussed by medical students who "atomize"²³ her.

Besides objectification, medicalization of illness means that adults find themselves suddenly limited in their autonomy and productivity. The ability to reason as an autonomous adult may be limited because of fever, pain, confusion or emotional responses to news of one's diagnosis. Diminished productivity is inevitable with many treatments such as chemotherapy for cancer. For example, in the same conversation informing Professor Bearing she has cancer she is told she cannot teach the next semester because of the side effects of her treatment.²⁴ If a side effect of the treatment of a chronic disease is fatigue or frequent absences for therapies such as radiation or dialysis, a patient's employability may be jeopardized. The medicalization of illness, with its emphasis on curing or treating the illness, takes precedence over the emotional and spiritual well-being of the person. This is the result of an increasingly data driven approach to healthcare. Friedman observes that including emotional variables in the

²² Edson, 36-37.

²³ Edson, 43.

²⁴ Edson, 11.

overall data would cause clinicians to see that the same procedure, though identically performed from a technical perspective, is actually different for every individual.²⁵

For too many sick persons the objectification of modern healthcare has led to isolation, stagnation and fear. While it may be lamentable that the Church is less and less influential in healthcare institutions, the realities of the post-modern and post-Christendom world paradoxically provide an opportunity for parish clergy to have an even greater impact on the well-being their parishioners. Hospitals are businesses, not ministries, but for an individual patient the involvement of clergy can make a great difference.

Moving beyond a data driven approach to healthcare complements a post-modern understanding of adulthood. Modern images of adulthood were influenced by Kant, Freud and Erikson among others.²⁶ An appreciation of these three perspectives is helpful to understanding how priests in post-modernity can advocate and intervene when a sick parishioner's treatments limit his or her personhood. The Kantian view of adulthood equates autonomy and autonomous judgment. Freud equated adulthood with the abilities to love and to work. Erikson, whom Schweitzer identifies as our main source for the modern understanding of the life cycle, emphasized generativity.²⁷ With the medicalization of illness, the experience of being a patient seeks to reduce an individual to undifferentiated data points. Adulthood is compromised by assumptions and assessments of one's faculty for autonomous judgment when clinicians and family

²⁵ Edwin Friedman, *Failure of Nerve: Leadership in the Age of the Quick Fix* (Church Publishing, Inc., 2007), 103.

²⁶ Friedrich L. Schweitzer, *The Postmodern Life Cycle: Challenges for Church and Theology* (Chalice Press, 2004), 82.

²⁷ Schweitzer, 82.

members debate what is best for the patient when the patient is unable to speak for herself or himself, or even when physical or mental limitations make conversation difficult and time consuming as with Sue Baier. Adulthood is compromised when patients are isolated either physically in critical care units or in rooms designed to prevent the spread of infection because isolation curtails the patient's ability to interact normally with those she or he loves, as with Donne. Obviously, limitations placed on patients because of their illnesses limit their ability to work but these can be exacerbated by the medicalization of illness as with Professor Bearing who could hardly teach or interact as a scholar when she was being examined by a former student. For many adults generativity is the key to their individuation. These examples of objectification and limitation of remarkable adults who were suddenly taken ill are powerful because their stories are powerful. Parish priests are able to penetrate the clinical barrier to traditional expressions of spirituality through their sacramental ministry and appropriate interventions, advocacy and presence. In so doing they can help their parishioner-patients discern for themselves what they can learn from their experiences of being sick as well as what is best for them as autonomous adults rather than only being subjected to the algorithms and best practices of contemporary healthcare.

In the following chapters, I will relate stories from my parish experience. These stories are based on persons I knew, prayed with, listened to and cared for deeply. Each has been fictionalized to protect anonymity and privacy. I have changed certain details including their names, diagnoses and descriptions of their conditions. I cared for these persons over a period of more than twenty years in various cities. All have died and none

has family in my current parish. I have taken care to preserve and share the lessons they taught me.

Chapter 2

Complementary Spiritual Care in Clinical Settings

At best a clinical understanding of spirituality is very different from that of parish priests and for patients whose spiritual formation—or lack of spiritual formation—occurred prior to the radical changes in religious institutions in the past forty years.²⁸ Philip's story illustrates how not addressing one's spiritual wellbeing, coupled with our disjointed delivery of healthcare, can have devastating consequences. Philip had lived half his life by 1970 and had a modern understanding of religion. He died alone. His death was as much precipitated by spiritual emptiness as physical disease. How and where he spent the last weeks of his life were determined by his health benefits through the Veterans Administration, Medicare and Medicaid, i.e. what his insurance would pay for. The lack of continuity of care may have contributed to when he died as well. Unfortunately the national debate about healthcare reform has been more an argument about its finance than a conversation about how to improve continuity of care or the spiritual wellbeing of patients.

Prior to recent changes in healthcare delivery and in American's dominant religious identity, it would have been safe to assume that an eighty year old man hospitalized with a stroke in a Southern town was a Christian, affiliated with a mainline denomination, and that he had a physician who knew him clinically. All that has changed and Philip was caught up in those changes.

When I met him, Philip was living in a high rise subsidized apartment building for seniors. He was referred to me by a lay minister who coordinated a weekly worship

²⁸ Diana Butler Bass, *Christianity for the Rest of Us: How the Neighborhood Church is Transforming the Faith* (Harper One, 2006), 43.

service in Philip's building. She told me he seemed to be seeking spiritually but had no one to guide him. When Philip was asked if he would like to talk with me, he sent word through the lay minister inviting me to stop by.

I visited with him for the first time in his sparsely furnished apartment the next day. After the briefest of introductions he told me matter-of-factly that he wanted to die. I learned that he was an alcoholic but had been sober for several years. He had been divorced from the now deceased mother of his only child, a daughter, who lived in New England and with whom he had very little contact. He blamed all this on his drinking. Philip lacked community. To my knowledge he had managed to quit drinking without the benefit of Alcoholics Anonymous. He told me he had been raised Lutheran but had never been part of a parish as an adult.

His only real friend was Gladys, the widow of a Presbyterian minister who lived on another floor of the high rise. They made a cute couple. Both were in their early eighties and looked their age but were not feeble. They obviously cared about each other and I wanted to believe they were enjoying an autumn romance. But as I got to know them, I realized that both Gladys and I were not so much trusted friends to Philip as we were means to an end. He was manipulative in a subtle and somehow endearing sort of way. I suspected this must have been how he had gotten through life.

It was clear to me that Philip knew I was neither going to help him die nor concede that he had nothing to live for. I was determined to help him whether he wanted help or not. We talked regularly and prayed together. I also scheduled a physical with a physician I knew through my involvement with hospice. His practice included geriatric patients whom he would refer to hospice when it was appropriate and continue to follow

them when some attending physicians transfer everything to the hospice Medical Director. He and his practice partner called their clinic *Caritas Family Practice*. The waiting room was decorated with religious images and, in addition to the usual dated magazines, there were tracts, religious magazines and Bibles scattered about. Philip had agreed to go when I offered to make the appointment but was like a small child when we got there. He insisted I go into the exam room with him. The result of the physical was that he was very healthy for his age. The physician told us he could imagine Philip easily living into his nineties if he managed his hypertension. He reviewed Philip's medications and prescribed a single medicine for his blood pressure and told Philip to discontinue the complicated mix of drugs he had been taking.

Gladys helped Philip get his medicine organized in a compartmented pill box. Each day's medicines were clearly marked. Philip still missed dosages. On New Year's Eve, he complained of such a bad head ache that an ambulance was called for him. His high blood pressure was treated and the emergency physician, unaware of the recent physical, gave him a new prescription. Thus began the final weeks of his life.

Since he was a veteran, Philip had asked to be taken to the local Veterans Administration emergency room. Once his blood pressure was controlled and his headache was better, Philip was told to take the new prescription to the hospital pharmacy so the cost would be covered by his veteran's benefit. After it was filled and he had his medication, he was to take a cab home. He did not go by the pharmacy. The next day Philip again suffered a terrible headache. This time Gladys called me. I took him back to the V. A. When we arrived, an intake coordinator did a brief interview and confirmed that his information was already in their system. We were told to wait. This

began twelve hours of waiting punctuated by calls to be evaluated by an ascending hierarchy of hospital staff. First, he was assessed by a triage nurse. Then a nurse practitioner assessed him. She was followed by an Emergency Medicine Resident who said Philip should be admitted to the hospital and told us to wait while he consulted with his Attending Physician. Eventually, we were called to another examining room so Philip could be assessed by another physician who would be his attending internist during his hospitalization. She agreed that he should be admitted and said we should wait for admissions to assign him to a room. Philip said that he did not want to be admitted. It was the first time all day he had said anything beyond answers to the same set of questions all his examiners had asked but now he was adamant. The attending admitted when pressed that she could not make him consent to the admission. She did tell him he had to stay until his blood pressure was within normal range. I finally took him back to his apartment at about eleven o'clock that night. The only thing that had changed was that I had helped get the prescription filled at the Veterans Administration pharmacy (which had no record of his previously prescribed medicines).

The next day Philip was taken by ambulance back to the V. A. and admitted to the hospital. He had suffered a stroke. He now had a specific diagnosis and the requisite number of days in the hospital to qualify for rehabilitative therapy and nursing home placement under his Medicare benefit. As soon as he was admitted to the nursing home, the staff insisted he complete a Medicaid application in anticipation of when his Medicare benefits would expire. When a nursing home patient or resident has no other pay source, room and board may be paid by Medicaid. For that to happen, Philip had to sign over to the nursing home his Social Security check and any savings he had. He also

had to give up his apartment. He knew he would spend the rest of his life in this nursing home. Because he was getting his medicines regularly, his blood pressure was controlled but he began to complain of horrible pain which was eventually diagnosed as shingles. He was given a steroid treatment and antiviral medication for the shingles which finally gave him some relief. During this time Philip asked me to serve as his Power of Attorney for both healthcare and financial matters. We completed the paper work on a Thursday. The next Sunday afternoon I received a call from the nursing home that Philip was dead.

It only took a few minutes for me to get to the nursing home but Gladys was already there. She was sitting quietly beside Philip's bed. His body had been straightened and the covers pulled neatly up to his shoulders. Unfortunately Gladys had arrived before the body was positioned and the bed clothes straightened. She saw him as he had been found. She told me that he seemed to have choked on his dentures. We comforted each other, prayed and wondered what had happened to him.

Philip had wanted his body given to a local medical school so I handled those arrangements. As his power of attorney, I had access to his medical records which I reviewed as I waited for the van to pick up the body for the medical school. Slowly I began to find clues to suggest why Philip had died the way he did. Gladys had mentioned once that Philip had been diagnosed in the past with myasthenia gravis. I remembered a connection with that disease and choking. When I looked at the National Institutes of Health website for information about myasthenia gravis, I read how it can cause breathing difficulty because of weakness of the chest wall muscles as well as chewing or swallowing difficulty, gagging and choking.²⁹ I consulted with a physician who

²⁹ "Myasthenia gravis," Medline Plus, U. S. National Library of Medicine, National Institutes of Health, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001731/> (Accessed November 14, 2011).

confirmed that my hunch may have been correct. Philip's death may well have been caused by symptoms related to his myasthenia gravis brought on as a result of steroids used to treat his shingles.

This is not to suggest that I am convinced this is what happened. My purpose here is to illustrate with Philip's story how disjointed our healthcare system is, how placement and treatment are influenced by money, and how patients' clinical information is not always available to those who need to know. The Veterans Administration pharmacist and physician did not have the record of Philip's complete physical and new medication profile. The physician who prescribed steroid treatment for Philip's shingles may not have known he had a history of myasthenia gravis.

Regardless of what the death certificate indicates, Philip's cause of death was more complicated than a single diagnosis. This is typically true. In his book, *How We Die*, Sherman, a physician, writes about the causes of death:

Whether its overt physical manifestation appears in the cerebrum or in the sluggishness of a senile immune system, the thing that peters out is nothing other than the life force. I have no real quarrel with those who insist upon evoking the laboratory-fed specificity of microscopic pathology in order to satisfy the compulsive demands of their biomedical worldview—I simply think they miss the point.³⁰

The *life force petering out* is certainly more descriptive than a diagnostic code. In the more than thirty years since I was ordained, I have seen many deaths beginning when I was nineteen and working my way through college in a hospital. When I was still in my mid-twenties and new to parish ministry, I was called in the middle of the night when a parishioner had suddenly and unexpectedly died. Since then I have lost count of the number of deaths I have attended. If my experience is typical, parish ministry always

³⁰ Nuland B. Sherman, *How We Die: Reflections on Life's Final Chapter* (Knopf, 1995), 44.

includes care of chronically and terminally ill parishioners. In addition to parish experience, I worked for a number of years as a clinical chaplain and in healthcare administration managing hospices, a hospital based palliative care service, and home health. Philip was referred to me because of that background. He did not have a congregational home beyond the one that met in the common area of his apartment building. That is where we did his memorial service. There is plenty in his story to show the inadequacies of our healthcare system but, after much thought, I have come to accept two important things about Philip and others who die alone. First, they lack someone who really listens. Philip told me that he wanted to die. He told me so within minutes of our first meeting. It would have been more beneficial to him for me to spend as much time as it took for him to tell me how he had reached that point in his life. Second, the *petering out of his life force* is a spiritual phenomenon.

I have wondered often whether I could have done anything more to help Philip. I knew his problems were spiritual in nature and that a person who lacks a spiritual home is not likely to find nurture in clinical settings. The physicians to whom I referred Philip are intentional about letting their patients know it is a Christian medical practice. Yet nothing was said or asked in his initial physical assessment about his spiritual life or, for that matter, his alcoholism. It was a *physical* examination. Besides that, he had a clergyperson with him in the examining room and he indicated on the questionnaire that he did not drink leading to the assumption his spiritual needs were being met and that he did not have an alcohol problem. Philip's case narrative illustrates the disjointed nature of the delivery of healthcare and of the way clinicians view spirituality. His story also

shows how even as well-intentioned and involved as I was, a clergyperson is limited when the relationship is not within the context of parochial and sacramental ministry.

Delivery of spiritual care in clinical settings is challenging. Marty has described spirituality as the term has come to be used clinically and culturally as “misty, evanescent, wispy and rich in appeal to narcissism.”³¹ Lutheran Bishop Stephen Bouman defines as neo-pagans those for whom the self or things of the world have taken the place of God. Bouman’s argument is that in their search for meaning and an aura of religion, “spirituality has become another addendum to the dreary litany of self-help projects, a matter of technique rather than immersion in the Word.”³² In the context of a pastoral visit with a parishioner, Bouman’s reflections speak to the inherent limitations of spiritual care by those who are not parish clergy:

What was I doing in that hospital room? Why was I there? If you read the plethora of books linking theology and psychology, you might think I was there as a “caregiver,” or a pastoral counselor, or a member of some healing “team,” or a participant in Clinical Pastoral Education using this encounter for my own growth and self-awareness. And each one of these roles might be authentic and appropriate at a given time. But they are not the reason I was there...I was not there to anchor her hope in her own techniques of “spirituality,” her tenacity as a good mother, or notions of a pervasive and formless spirituality inherent in all of life.³³

Marty and Bouman represent a cynical take on cultural understandings of spirituality from their perspectives as pastors. The challenge for clergy is that literature about spirituality addressed to clinicians “reflects an understanding of spirituality that is void of religion, an instrument to be utilized in improving or maintaining health and

³¹ Martin Marty, “Getting Organized,” *Christian Century* 113 (April 17, 1996): 439.

³² Stephen P. Bouman, *From the Parish for the life of the World* (Augsburg Press, 2000), 62.

³³ Bouman, 99.

quality of life, and is primarily focused on spirituality as it relates to the individual, namely the patient.”³⁴ Literature by and for clinicians also recognizes the challenges to spiritual care in clinical settings by clinicians. Indeed, much research on spirituality by physicians, nurses and social workers has been published in peer reviewed journals but a thematic review of the literature reveals the conceptual ambiguity of the term. This conceptual ambiguity is itself the point of greatest unity in the literature.³⁵ The research of Sinclair, et al., looked at the research related to spirituality and health in the past twenty years. They identified three approaches to defining spirituality: first, the concept evades language and should be treated conceptually; second, there are broad and ambiguous working definitions; or third, restrictive and focused definitions are proposed.³⁶

The good news is that the same review found great interest in and appreciation for spirituality and spiritual care in clinical settings. It has been my experience that clinicians welcome my involvement when there is a relationship of trust based on their experience of me in their settings as will be illustrated by another case narrative below. However, these relationships take time and opportunity to establish. As with Philip, for patients who are caught up in the system, pastoral visits necessarily occur over a continuum of clinical settings. I interacted with him in a physician’s office, an emergency room, a hospital intensive care unit, and a nursing home. Each of these settings had different staff and in each setting he was under the care of a different

³⁴ Shane Sinclair, Jose Pereira, and Shelley Raffin, “A Thematic Review of the Spirituality Literature within Palliative Care,” *Journal of Palliative Medicine*. 9, no. 2 (2006): 465.

³⁵ Sinclair, et. al., 466.

³⁶ Sinclair, et. al., 466.

physician. Although visibility is critical to a parish priest becoming an integral part of the team who are delivering health care, just visiting parishioners when they are in clinical settings is not enough. Clergy must also take the initiative to integrate our understanding of spirituality into the plans of care for individual patients. Even in church affiliated hospitals, this integration must start not with a parochial understanding of religion but with the clinical understanding (or lack thereof) of spirituality.

An excellent starting point for dialogue between clergy and clinicians is death. I typically wear clericals when visiting parishioners. Not only have I seldom experienced any difficulty in gaining access to parishioners but I have been asked to help when other patients have died or who have been given a poor prognosis. In a system dedicated to the preservation of life, a priest is uniquely qualified to *do something* when a patient dies, as inevitably some do. When Philip told me he was ready to die, I was no more ready to hear that or pursue its meaning to him than any of the others he encountered during the final three months of his life. There are voices of reason within the clinical community who believe the inevitability of death is an opportunity for despair in the face of oblivion but, paradoxically, it is also a pathway to hope and meaning in life. Ira Byock is a physician and leader in the palliative care movement in this country who has championed the importance of clinicians understanding the transcendent. He represents many clinicians who, though they may speak of spirituality in terms that are too vague for parish priests, nonetheless are willing and even eager to address the transcendent:

As a clinician it seems disrespectful to discuss the “meaning and value” of death. The preciousness of life underlies all clinical disciplines and preservation of life is a paramount clinical goal. Understandably, for clinicians death is the enemy to be conquered and when it occurs it represents defeat, failure.

Phenomenologically, death is non-being. The essential nature of life entails activity, purpose and making order from disorder. Death is the antithesis of life. Non-life is inactive and despite its stillness, death is chaos. Life generates its own meaning. In contrast, on its face death appears devoid of meaning and value.

Since, philosophically I cannot know anything with certainty about death, I must accept that death itself may (or may not) be meaningless. Nevertheless, it is apparent that the fact of death profoundly impacts our understanding—and experience—of meaning *in life*. Although it remains unknowable, death's relationship to life is essential and as profound as the relationship of darkness to light. Death need not illuminate life; it is sufficient for death to provide the background against which the light of life is seen. It is from this perspective, both clinically, and philosophically, that the question: "What is the meaning and value of death?" becomes relevant and approachable.³⁷

When dealing with death in clinical settings, as parish priest inevitably will, there is an opportunity to engage clinicians. Care must be taken to avoid platitudes at the time of death and to provide sacramental care and pastoral conversation that do not appear routine or trivial. It takes a measure of courage to speak of the meaning and value of death if, as Byock observes, to do so seems disrespectful to clinicians. For clergy, it takes a measure of courage to risk becoming a resource for patients, families and clinical staff who face death. It also takes tact, timing and intentionality. Working together with clinicians, parish clergy have the potential to bring to healthcare a parochial approach to spirituality which offers not only specific sacramental and scriptural resources to utilize when seeking to find meaning in suffering and death, but also provides a framework for a lifelong discipline for spirituality beyond the clinical setting.

Byock uses anecdotes from his experiences as a hospice physician to illustrate the importance of five simple and everyday phrases: "Please forgive me." "I forgive you."

³⁷ Ira Byock, "The Meaning and Value of Death," *Journal of Palliative Medicine* 5, No 2 (May 2002): 279.

“Thank you.” “I love you.” And, “Good-bye.”³⁸ Remembering that good-bye is derived from “God be with you,” his *four things that matter most*, i.e. forgiveness, gratitude, love and blessing, are inherent in Christian liturgy and consistent with the what Markham calls liturgical life principles. These principles find expression in liturgy, the whole purpose of which is “to provide the resources to enable God to facilitate health and authentic living—healthy in mind, body, and spirit and authentic in recognizing the realities of being a mortal creature in this world.”³⁹ Byock, who describes himself as a non-practicing Jew, reflecting on spirituality in palliative and end-of-life care, concludes that “human life is inherently spiritual, whether or not a person has a religion.”⁴⁰ It is unnecessarily polemic to insist that clinicians and parochial clergy do not share a sort of higher ground in that both agree there is something transcendent in genuine humanity and the human ability to love. For Byock “the love of two people can...be a fiercely defiant act, for love affirms life in the face of death,”⁴¹ and for Markham the “cross reminds us that Christianity does not equate healthy living with a pain-free, suffering-free existence.”⁴²

When parish clergy are integrally and vitally involved, when their counsel and pastoral interventions are valued and recognized as resources, patients can truly experience holistic care, i.e. care provided for the body and soul that is not on parallel trajectories but are complementary and intentional. An example of a patient who had the

³⁸ Ira Byock, *The Four Things That Matter Most: A Book About Life* (Free Press, New York, 2004), 6.

³⁹ Ian S. Markham, *Liturgical Life Principles: How Episcopal Worship Can Lead to Healthy and Authentic Living* (Morehouse Publishing, 2009), 12.

⁴⁰ Ira Byock, “To Life! Reflections on Spirituality, Palliative Practice, and Politics,” *American Journal of Hospice and Palliative Medicine* 23, No 6 (December/January 2007): 437.

⁴¹ Byock. To Life! 436.

⁴² Markham, 31.

benefit of both quality medical care and traditional religious spiritual support is Grant Turner Jeffery whose daughter-in-law, Margot E. Fassler, chronicled his final days as a case study. A professor of music history at Yale University, Fassler concluded that liturgical elements present in Mr. Jeffery's final days constituted a "mode of dying (that) provides an important case study of the sort needed...to engage the subject of dying more broadly by liturgical scholars, liturgists, and church musicians."⁴³ It can also illustrate how a clinical understanding of spirituality and a traditional expression of spirituality using the language of Common Prayer need not be antagonistic.

Mr. Jeffery had been in his youth a Trappist novice who left the monastery but always attended daily mass. When he was given a very poor prognosis and admitted to an in-patient hospice facility, the prayers which had been so important to him throughout his life continued to give strength to him and to his family. Fassler describes how the Sacraments, scripture, liturgy and music became all the more central to him as he was dying. Each day he was in the hospice facility, at around nine o'clock in the evening, his day would end with the words, "*Benedicamus Domino*," to which she would respond, "*Deo gratias*." The hospice's attempt to meet the spiritual needs of its patients and their families included providing a chapel but in the chapel there were no Christian hymnals. In the days leading up to his death, Mr. Jeffery's family and clergy brought books of scripture and prayer to him. Fassler's account of his death was one he fashioned for himself. He "died gloriously because he made all the ingredients of our Great Church

⁴³ Margot Fassler, "Liturgical Elements in the Hospice Sickroom: A Case Study," *Worship* 73, no. 3 (1999): 236.

Year into a Great Church Week, drinking from the fountain of a life which is the liturgy.”⁴⁴

Clearly Mr. Jeffery was an exceptional man whose lifelong spiritual discipline had been witnessed by his family and faith community but the comfort he found in the common prayers of the Church need not be limited to only those who are extraordinarily pious. After a friend was diagnosed with stage IV esophageal cancer, he told me that knowing he would die soon caused him to realize that he really did believe what he had been praying as a faithful Episcopalian. There was no viable surgical option because his tumor was on his esophagus but for three years he kept the cancer at bay through chemotherapy and continued to work, play and pray as he always had. His spirituality complemented his medical treatments. Clinicians will value the Sacramental ministry of parish clergy when it could be understood by them as complementary therapy which helps patients cope during the course of an illness or treatments.

⁴⁴ Fassler, 244-245.

Chapter 3

The Role of Clergy in Palliative Care throughout the Continuum of Treatment

A parish priest can only be integral to the care of a parishioner if the care is palliative. Here the priest may very well have a better understanding of palliative care than clinicians who too often equate palliative care with end of life care. This is due to the association of palliative care with hospice. However, there are a growing number of hospital based palliative care programs that extend the availability of palliative care beyond patients who are dying. According to the Center to Advance Palliative Care, the number of hospitals with fifty or more beds offering palliative care programs increased from 24.5% in 2002 to 58.8% in 2008.⁴⁵ The Center to Advance Palliative Care offers intensive training at their various Centers of Excellence which serve as models for hospital based palliative care.⁴⁶ Physicians are being certified in palliative medicine as a subspecialty of a number of general specialties by the American Board of Medical Specialties. Ideally, because of its holistic, interdisciplinary approach and aggressive symptom management, palliative care offers hope for autonomy and dignity at the end of life as well as diminished suffering for patients with chronic illnesses.⁴⁷ However, the proliferation of programs and certifications has not successfully changed the bias of

⁴⁵ Center to Advance Palliative Care, "Making a Case for Hospital Based Palliative Care." <http://www.capc.org/building-a-hospital-based-palliative-care-program/case> (accessed December 6, 2011).

⁴⁶ Center to Advance Palliative Care, "Building A Hospital Based Palliative Care Program." <http://www.capc.org/building-a-hospital-based-palliative-care-program> (accessed December 6, 2011).

⁴⁷ Center to Advance Palliative Care, "New Dartmouth Study Shows Need for Better Management of Chronic Illness," <http://www.capc.org/news-and-events/releases/May-2006-release> (accessed August 12, 2007).

palliative care as a mode of care for only terminal and chronically ill patients with extreme symptom management issues or complicated discharge planning challenges.

There are various organizations that advocate for palliative care and have published definitions of the word. In each case the definition includes spiritual interventions. For example, the World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁴⁸ In the United States, the National Consensus Project, whose member organizations include the National Hospice and Palliative Care Organization and the Center to Advance Palliative Care, defines palliative care as “medical care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, nutrition, rehabilitation, pharmacy, therapists, and other health care professions. It further aims to identify and address the physical, psychological, spiritual, and practical burdens of illness.”⁴⁹ It is a natural fit for parish clergy to approach the cure of souls holistically with an obvious emphasis on spirituality. Parish clergy also have an awareness of the impact of an illness on the patient’s family and larger community. Parish clergy have the unique advantage of being with their parishioners in their homes. With the exception of hospice and home health providers, no clinician routinely visits homes.

⁴⁸ World Health Organization, “World Health Organization Definition of Palliative Care.” www.who.int/cancer/palliative/definition (accessed August 12, 2007).

⁴⁹ National Consensus Project for Quality Palliative Care, “What is Palliative Care?” www.nationalconsensusproject.org/WhatIsPC.asp (accessed August 23, 2007).

There are generally two limitations to parish clergy having access to hospitalized patients. One is the different understanding of spirituality discussed above in the previous chapter. The other is legitimate concern on the part of hospitals to protect patient confidentiality. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule provides for protection of personal health information (PHI) held by covered entities, including hospitals, and gives patients rights with respect to their PHI.⁵⁰ The law provides for disclosure of PHI as necessary in the provision of patient care or for other purposes such as accreditation surveys and exchange of information necessary for reimbursement for services. Hospitals were quick to implement policies protecting PHI and defining who would have access to it. The motivation to adhere to these policies is that the Federal Office of Civil Rights enforces the HIPAA privacy rules.⁵¹ Patient privacy and confidentiality were always important but HIPAA elevated the issue. Since the implementation of HIPAA related policies it is often more difficult for clergy to get information about parishioners who are hospitalized or even that a parishioner is hospitalized. The practice of providing clergy with copies of a hospital's census broken down by religious affiliation is not as widespread as it was before HIPAA. Clergy groups and hospital pastoral care departments have worked with hospital administrators to overcome the challenges. A better approach than arguing for community clergy in general to have access to PHI is to take an individual approach. Parishioners must be encouraged to notify their priest when hospitalized and should include in their Advance Directive a provision for their priest to have not only

⁵⁰Department of Health and Human Services, "Understanding Health Information Privacy," <http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html> (Accessed December 9, 2011).

⁵¹ Department of Health and Human Services, "Enforcement of the Confidentiality Provisions of the Patient Safety Act," www.hhs.gov/ocr/privacy/psa/enforcement/index.html (Accessed December 9, 2011).

information about admissions but diagnosis, prognosis and treatment plans as well. Even with this document, patients and their families will need to tell attending physicians and hospital personnel about the desire to involve their priest in the care team.

Once a priest or deacon has demonstrated an ability to help the clinical team, he or she will be welcome. Gary's story illustrates both how a parish priest was able to work with a physician to get palliative care and how, if the priest had had more information about the prognosis and diagnosis, the priest could have been a greater impact sooner. Gary was a parishioner who suffered from the same disease Senator Edward Kennedy had, glioblastoma. Glioblastomas are the most aggressive type of brain cancer.⁵² Gary desperately needed palliative care from the time of his diagnosis which, unfortunately, occurred when the parish only had a supply priest. Soon after arriving, I heard that we had a parishioner who was homebound due to a stroke. I visited Gary for the first time when I learned that he was in the hospital (the first of three hospitals in which I would eventually visit Gary). The disease was already advanced and caused him great difficulty speaking. It was clear that he knew what he wanted to say but he was unable to complete his sentences. This was incredibly frustrating for Gary and meant that I had to sit with him for extended periods to get even a glimpse into what he was experiencing. To complicate matters more, his only family were his wife, Maria, who did not speak English well, and his eighty year old mother, Ruth. The three of them lived in the same house. Soon after Gary and Maria married, they moved from another city because of his job. Shortly after that, his sister died and they took Ruth in. Maria resented her mother-in-law and was angry about her situation. Ruth felt that she was a

⁵² National Institute of Health Medline Plus, "Brain Tumor-Primary-Adults," www.nlm.nih.gov/medlineplus/ency/article/007222.htm (Accessed January 4, 2012).

burden but was unable to move into a place of her own. She was still grieving her daughter as she helped care for her terminally ill son.

Gary's physical symptoms and complicated family situation made him an excellent candidate for palliative care. Physically, Gary's chief complaint was his inability to speak in complete thoughts even though it was perfectly clear that he knew what he wanted to say. The best visit he and I had was when I found him alone in the hospital late one afternoon. I sat by his bed for an hour and listened as he struggled to tell me about his hobby. He was a Civil War buff who participated in re-enactments. He had played the part of a Confederate Chaplain. I did not understand any of this at the time but we both were able to enjoy each other's company. Typically, his wife or mother would try too hard to help Gary finish his thoughts and he would simply give up. On this occasion, even though the part about his being a priest was confusing, he was able to laugh a bit and was not as frustrated as he usually was. Later I asked Ruth what he meant when he said he had been a priest. She explained that had been the role he played in the re-enactment. A palliative approach to caring for Gary would have combined medical, emotional, social and spiritual aspects of his condition. Was everything possible being done to help him communicate? Was he given adequate time to get his thoughts out and were family and staff empathetic listeners? How could the spiritual needs of one who loved the Prayer Book but was unable to speak complete sentences be addressed?

Ruth and Gary were lifelong Episcopalians. Even this made his wife, who was Roman Catholic, jealous of my attention. It was very difficult for me to piece together bit by bit what was happening to Gary physically and otherwise. For example, Gary and his wife were in agreement that he could be healed if they could only find the right physician

or therapy. His wife was convinced they should have gone to Mexico for treatment. She also wanted Gary to be seen by a local physician who was known for nutritional therapy. Their house was in foreclosure because they had gone through whatever savings they had.

The dearth of information available to me about Gary's diagnosis and prognosis, his PHI, meant that I was unable to help as much as I would have been otherwise and that what I did was not particularly helpful. For example, I organized volunteers to build a ramp at Gary's house and used discretionary funds to pay for the materials. Gary had managed to tell me that he wanted to get outside and his wife told me she was getting a special mechanical chair for him. The ramp was never used.

One day Gary's mother called to let me know they had called Emergency Medical Services to the house. Gary was admitted to the local hospital and was in the critical care unit. When I arrived Gary's speech had deteriorated even further. I was able to figure out that he wanted me to arrange for him to be transferred to a University hospital. It was the last conversation we would have. As it turned out, I was in the room when the physician arrived. She was an internal medicine specialist employed by the hospital. She did not know Gary prior to this hospitalization. Gary had been hospitalized numerous times at hospitals in two other cities but never at this one. When she entered the room, the physician ignored me. She introduced herself to Gary's wife and said she needed to talk to her. I spoke up and asked Maria if I should excuse myself or whether she wanted me to hear what the physician had to say. Maria said that she wanted me to stay. The physician asked Maria specifically for permission to discuss Gary's confidential information in front of me. When Maria agreed, I was immediately included in the

conversation. Maria was told that Gary's cancer had progressed and spread and that he was dying. For the first time, Maria seemed to accept this. I asked the physician if she wanted to refer them to hospice and she responded that she did. Maria asked if she could have some time alone with me before she signed authorization for the physician to write an order not to resuscitate Gary when he stopped breathing. The staff referred to this as "making him a DNR." Gary was transferred to a hospice inpatient unit close to their home where he died a few days later.

Palliative care involves aggressive symptom management and treating the patient holistically as well as caring for his family. Gary needed this approach to his care. There were physical symptoms including diarrhea and headaches. He needed emotional support from someone who knew him well enough to know that he was not simply in denial but that fighting the cancer was completely in character for him. Gary had had polio as a child and heart disease as an adult. He was used to getting bad news and overcoming poor prognoses. Gary's family situation was complicated. He needed practical help because of the imminent foreclosure. And, spiritually, he needed the comfort of sacramental ministry from an Episcopal priest with whom he had a pastoral relationship. Ultimately, I was able to help but his final months of life might have been much easier for him and for his family if he had given instruction at the time of his diagnosis to include his priest as an integral part of his care team.

As a clinical chaplain, I have been contacted directly by clinicians and asked to become involved with patients. Examples include a patient with advanced pulmonary disease who was not responding to treatment. Her pulmonologist called me saying that the only intervention that will help her was a spiritual one. Another such invitation came

from the heart transplant coordinator at the hospital where I did my Clinical Pastoral Education residency. In that case, I was told the patient was an excellent candidate for a transplant except there was something wrong that could not be measured clinically. When chaplains are involved, they have access to information and they often have the skills and experience to be very helpful. I believe my ministry as a chaplain was beneficial. But Gary's story illustrates how it is parish priests who know patients over time and more intimately. Gary died about a year after being diagnosed. He was admitted to four different hospitals in four different cities. The neurologist and oncologist who knew his case best were competent and honest with Gary and Maria. If I had been included initially as I was eventually, I would have been much more effective pastorally.

I received the call at two o'clock in the morning that Gary had died. Ruth was alone at his bedside when I arrived at the hospice unit. We prayed the Litany at the Time of Death.⁵³ When we had finished the prayers, I heard the rest of Gary's story. There was an important piece of information about Gary that she mentioned casually as she talked about her son's life. That is when I learned that he had polio as a child and that he had serious heart disease as an adult. Gary had fought for his health his entire life. He fought the effects of polio and he fought the heart disease. He had made it very clear that he wanted a heart transplant if it came to that. So, when he was diagnosed with the glioblastoma, he could not have been expected to accept death without a fight. It was not a lack of faith or denial. It was just how Gary dealt with illness.

⁵³ *The Book of Common Prayer*, 462-464.

Chapter 4

Sanctification of Illness Requires Shift from Data Driven Decisions to Personal Discernment

For Anglicans “the core of human dignity lies in the relationship to God rather than in qualities of intelligence or free will.”⁵⁴ The medicalization of illness with its data driven decision making and objectification of the sick diminishes patients’ individuality and, therefore, dignity. It fails to take into account the importance of how a unique life story intersects with the narrative which is the human experience. Parish priests who practice their ministry with and for the sick with intentionality and confidence are able to help the sick but they also lead parishes into a vital sense of mission to minister to the sick. Almost thirty years ago Gerkin recognized the need in pastoral counseling for a return to narrative. An individual in crisis finds meaning not in cognitive awareness but in a realization of shared language and images.⁵⁵ When a sick parishioner is caught up in the medicalization of illness and his or her priest enters into that experience with sacraments, prayers and scripture, the priest does for one individual what the Church is called to do for the world.

Visiting the sick is a core responsibility of parish clergy. Attention to that responsibility gives clergy a foundation from which to build. It helps clergy to establish credibility and inspires loyalty. Before a priest can be prophetic, she or he needs to be a pastor. For example, Tyson describes how his father, a United Methodist pastor in Oxford, North Carolina, with a passion for civil rights, responded to the lynching of an African American. The lay leadership of the parish were willing to listen to him on this

⁵⁴ Smith, 10.

⁵⁵ Charles V. Gerkin, *The Living Human Document: ReVisioning Pastoral Counseling in a Hermeneutical Mode* (Abingdon, 1984), 43.

and able to support his invitation of an African American guest preacher, not because of the power of their pastor's prophetic argument, but because he faithfully visited the elderly parents of the conservative businessmen of his Administrative Board.⁵⁶ It is in caring that community is nourished.

In the Anglican tradition our identity is formed through ritual. By ensuring that persons who are unable to be a part of their parish's liturgical life because of sickness receive sacramental care, the formative rituals continue to give dignity and community even to those physically isolated and institutionalized. Baptism is the ritual context in which our adoption as sons and daughters of God is declared a reality and, through Eucharist, this declaration is continued. Our rituals attest to identification between Christians and God incarnate. For Anglicans "human dignity is derivative; at the very least it would be hard for Anglicans to hold that a being who might be baptized was lacking in human dignity."⁵⁷

This is good news not only for individuals in pain but for their parishes as well. Both individual Christians and parishes benefit when clergy practice excellence in sacramental care of the sick for the following reasons. First, spiritual growth is not tightly linked to psychological development.⁵⁸ Bringing communion, anointing and prayers to the sick serve as living reminders of who we are as a part of a sacred community and can give meaning to our suffering because salvation "does not mean an

⁵⁶ Timothy Tyson, *Blood Done Sign My Name* (Crown Publishers, 2004), 78.

⁵⁷ Smith, 10.

⁵⁸ Robert D. Hughes, III, *Beloved Dust: Tides of the Spirit in the Christian Life* (Continuum, 2008), 193-194.

end to suffering; it means an end to *isolated* suffering.”⁵⁹ Second, as a generation of clergy has had to re-learn how to preach with the evolving post-Christendom loss of ecclesiastical authority, incorporation into the ritual community and sacramentally infused care of the sick transcends such limitations. Third, as leaders of the old mainline liberal denominations struggle to figure out whether to compete with mega-churches and what exactly the emergent church is, our identity as a community of faith is continually affirmed through traditional liturgical words and actions. When a priest takes communion to a sick parishioner and listens to that person’s unique account of what is happening in her or his life, the questions of authority and mission evaporate. Ironically the much lamented graying of parishioners may be the very thing that brings a vital sense of mission and vitality to a parish. Consider the people in the group referred to as the third age, i.e. older adults who are frail and do not need to be taken care of but who have met their parenting responsibilities and for whom their livelihood is no longer tied to productivity. Schweitzer argues that to the extent this new developmental phenomenon exists some have come to realize the developmental possibilities for this stage. My parish is representative of many in this way. We have a number of retired older adults who are energetic and fully engaged in the community. “Practical theology as a midwife to postmodern old age—the Third Age—must do the following: first, help this age to come about by making space for it; second, help people to reflect critically on modern ideologies that equate adulthood with independence. . . ; and, third, make available alternatives to old age consumerism.”⁶⁰ This group of older adults is a logical starting point for a ministry aimed at helping parishioners overcome the medicalization of illness.

⁵⁹ Smith, 8.

⁶⁰ Schweitzer, 109.

Parishioners in this stage of life have much to offer. On the on the other hand, it is during this time when episodic illness occurs and when one expects sooner or later to encounter chronic illness and a terminal disease. Led by informed clergy, entire parishes can embrace a ministry with and for the sick that does far more than just visit hospitals and nursing homes.

As Jewel's story illustrates, with forethought and the help of an involved and caring parish, a person of this age can prepare for a good death. Mrs. Jewel Matthews was aptly named. She was a beloved jewel as the matriarch of St. Luke's Church. I said as much at her funeral. I knew Miss Jewel was a remarkable woman the first time I visited her home. She was eighty-nine years old and bedbound due to the degenerative disk disease that complicated an old back injury. She was also nearly blind from macular degeneration. But Miss Jewel's mind was clear and her will was as strong as ever. Her personality and character were evident in our initial visit as she told me about her first solo flight when she was a young woman. Mr. Matthews had been a pilot and the manager of a nearby airfield in the 1940s. Jewel had talked him into teaching her to fly. When she soloed for the first time there was a malfunction in the single engine plane. She was forced to react and land the plane under nerve-wracking conditions. She told the story with animation and obvious pleasure. And I was enamored with her from then on.

Jewel had been widowed relatively young and had no children. She had gone to work for the state as a bookkeeper. She was injured on the job by a fall when she was in her sixties and had to retire. She was still bitter about how she had been treated by the state. She owned the small home where she and her husband had lived. For a time after her husband died, Jewel had lived with and cared for her sister whose health had

gradually deteriorated. Jewel cared for her until her death. In gratitude for what Jewel did her sister had made Jewel the beneficiary of the estate, so she inherited her sister's much nicer home. Jewel's experience caring for her sister made her realize that if she wanted to avoid nursing home placement when she was unable to care for herself, she would need to manage her resources, including this inheritance, so that she could hire caregivers. She sold her sister's house and moved back into her own more modest home even though by that time the neighborhood had started to deteriorate. When I knew her, Jewel was completely dependent on a team of caregivers she had hired and managed from her sickbed. As our relationship grew, she informed me that her money would be exhausted a few months after her ninetieth birthday. She confided that her desire was to die in her own bed before that happened.

Helping her stay home became a cause for the parish. The best option we came up with for Jewel was a reverse mortgage on her home. It was a viable short term solution since it would give her the equity she had in her house to pay her caregivers for a few more months. Jewel's house would be her primary estate. It would go to her twin sisters who did not need the house and would have trouble selling it. But Jewel was skeptical about taking a mortgage on her home. I got the information for her but did not force the issue.

Miss Jewel was an intelligent, resourceful woman whose body was failing but whose mind, community and spirituality were strong. All three were put to the test by the healthcare system in the final weeks of her life. Miss Jewel had to be admitted to the hospital through the emergency room when she got into a pain crisis. I learned that Jewel had been taking half her pain medication in order to save money. When I visited her in

the hospital she told me that she weighed eighty-nine pounds. I asked how they were able to weigh her. It was obvious she could not stand on a scale. She said they had brought a sling contraption attached to a scale. She was hoisted from her bed into this sling to be weighed. She also told me they had put her through a CAT scan. I asked about that experience. She said it was bad. The noise and tightness of the machine were so frightening that she closed her eyes as tight as she could and prayed until it was over. After causing her to endure the pain and indignity of these procedures, her physician had data to show that she was a tiny woman with an old back injury and disk disease. All of which he knew before her hospitalization. She was discharged back home with exactly the same pain medication prescribed as she had before. Nothing changed as a result of the hospitalization. I contacted his office to ask for a referral to hospice so that Miss Jewel would have adequate pain management and additional help to stay in her home. Part of the Medicare hospice benefit is medication to manage symptoms, including pain. These medicines and all the services for Medicare hospice patients have no out-of-pocket cost to the patient. Unfortunately, her physician would not talk to me or to anyone from the hospice. He had someone in his office tell a hospice representative that he would not refer her to hospice because she did not have cancer. The only requirements for a hospice admission are a prognosis of less than six months and the patient's desire for hospice care. Hospice does not require a cancer diagnosis. However, hospice cannot admit a patient and provide any care without certification by the patient's attending physician of a terminal prognosis, i.e. less than six months life expectancy if the disease

takes its expected course.⁶¹ Since her physician was unwilling to do this and since Jewel was not open to changing physicians, hospice was not an option for her.

Jewel was fortunate. In the last weeks of her life, she was able to remain in her home with the care of her trusted caregivers because of interventions and support of her parish. A nurse in the parish told a physician about Jewel's situation. He was willing to prescribe adequate and affordable pain treatment. Jewel enjoyed her ninetieth birthday. Friends from St. Luke's brought her a cake and surrounded her bed singing "Happy Birthday" as she blew out candles shaped like a nine and a zero. Because she was confined to her bed and had very limited vision, they bought her a warm blanket that felt good against her skin. About six weeks later, wrapped in that blanket, Jewel died early one morning. When I arrived her seventy-eight year old twin sisters and several of her caregivers and friends from St. Luke were already in her living room. I remembered our last several conversations when Jewel had told me she wanted to die before her money ran out and she would have to go into a nursing home as a Medicaid beneficiary. She had figured out she could pay her help through October. She died on Labor Day.

Jewel could have had a fate similar to Philip's. Like him she could have died alone in a nursing home. The difference in their stories is that she had a spiritual identity that grew out of a lifetime of participation in rituals of the church and she was afforded the ministry of her parish. It is true as Bouman says, "In baptism the only death you need fear is behind you."⁶² Jewel's generation had seen tremendous advances for women. She had to get her husband's permission to fly solo but she did it. She had to rely on her own

⁶¹ Medicare Benefit Policy Manual, Chapter 9, "Coverage of Hospice Services under Hospital Insurance," Center for Medicaid and Medicare, <https://www.cms.gov/manuals/Downloads/bp102c09.pdf> (Accessed September 14, 2011).

⁶² Bouman, 52.

resourcefulness and prudence in order to live in her own home. But in the end, while she was not afraid of death, she avoided what she did fear, institutionalization, because of the involvement of her priest and parish beyond simple friendly visits. When her physician would not accept me as a part of her team, her sister in Christ found another physician who would listen and prescribe adequate pain medicine. We refused to accept medical paternalism or to buy into the medical model that is driven by what is reimbursable, e.g. a Computerized Axial Tomography (CAT scan). “When the Church buys into the pervasive contemporary medical model, it becomes another social service agency, treating symptoms, feeding dependency, diagnosing the ills of the other, and applying the approved remedy....Communally, the medical model...fosters abject dependence on the programs of strangers.”⁶³ This happened to Philip but not Jewel. She died a good death in her own home surrounded by biological and spiritual sisters.

Another element of the medicalization of illness is a phenomenon reminiscent of the story of Job. When everything was taken from him and Job was miserably scratching his wounds, a chorus of family and friends started bewailing him with their interpretation of the data. It started with his wife who said, “Do you still persist in your integrity? Curse God, and die.”⁶⁴ It continued with his friends. For example, Zophar the Naamathite asked him, “Should your babble put others to silence, and when you mock, shall no one shame you? For you say, ‘My conduct is pure, and I am clean in God’s

⁶³ Bouman, 115.

⁶⁴ Job 2; 9. *New Revised Standard Version*.

sight.’ But oh, that God would speak, and open his lips to you, and that he would tell you the secrets of wisdom!”⁶⁵

More than anyone I’ve known in my ministry, Mike reminded me of Job. He suffered much and was surrounded by family and friends, including me, who wondered aloud why he kept fighting his cancer. This is not exactly the same as Job’s friends telling him to curse God and die; but in retrospect I can see how Mike’s strong faith and brilliant mind helped him to see something the rest of us did not.

My relationship with Mike was complicated but comfortable. At the time, I was managing a hospice and serving a small inner-city congregation. Mike was very active in a larger parish I had attended before accepting the call to my parish. This meant that Mike knew me as a friend who was both clergy and a hospice administrator. When he was diagnosed with metastatic bone cancer, my assumption was that he should be on hospice immediately. I remember a conversation with a mutual friend, a physician, in which we both agreed he should stop the chemo and radiation therapies and sign on to hospice. This way he would avoid the side effects of the treatments and get his bone pain managed. Mike’s wife talked to me about what hospice would do for him when he was ready to accept it. I remember her telling me how long it took to get him dressed and ready to go for his outpatient treatments. I offered to help her get him dressed and to the car but she explained that she did not need help getting him dressed. He could dress himself and walk to the car. It took so long because he was in such terrible pain.

One night I received a call that Mike had been admitted to a local hospital and was not expected to live until morning. The hall outside his room was already filled with friends when I arrived. Mike was a research scientist and an accomplished musician who

⁶⁵ Job 11; 2-6.

was devoted to his wife and family. The crowd in the hall was evidence of the way he had lived his life. I went into his room. There his wife, their children and grandchildren were gathered. Mike appeared to be in a deep coma. This was a scene I had witnessed many times and, like everyone else, I believed Mike would die soon. There was a sense of relief that his suffering was over.

After a while, I went home. The next morning I called the hospital before going. I wanted to confirm that he had not died during the night. I was a bit surprised when the operator offered to ring his room. Knowing how exhausting a deathbed vigil can be, I opted to go to the hospital rather than having the phone in Mike's room ring. I have seen a lot but I never expected what I found when I entered the room. Mike was sitting up and talking to his wife. Her face registered both joy and dismay as she told me the story. Eventually during the night everyone left and she was alone at Mike's bedside. She had drifted off to sleep. As the morning sunshine started to fill the hospital room with light, she was awakened by Mike's voice wishing her a happy birthday.

Mike was discharged from the hospital a few days later and sent home with a referral to my hospice. I chose to do the initial paperwork with him myself. I explained the services we provided and his rights as a hospice patient which included the right to revoke our services. Fortunately for Mike, before being admitted to the hospice, his oncologist had put him on an intrathecal pump, a device Mike wore that injected narcotic pain medicine directly into his spinal fluid. He was the first patient we had admitted with a pump directly connected to the spinal column. I was not even sure my nursing staff had the training to manage it. As it turned out, the pump was not difficult to manage and Mike tolerated it well. This mode of treatment gave him relief from his pain for the first

time in weeks. With his pain finally relieved, Mike told me he wanted to revoke hospice and get more treatment. With the additional therapy his cancer went into remission long enough for him to resume his life. Five years later, he was again close to death but in the interim he had enjoyed life. A short time before he died, he and his wife were honored with a reception for their fiftieth wedding anniversary. I received the following note after his funeral:

Dearest Joe and Kathy, How pleased Mike would be to know you contributed to Concerts with a Cause in his memory! He was on both the committee which hired Jamie (the church music director) and the organ committee. Joe, he was so very pleased to get your letter. I know he intended to write, but cannot recall whether or not he did. Your support and prayers from early on in the metastatic stage of his illness was such a blessing to both of us! ...I shall miss Mike for as long as I live but I give thanks for fifty wonderful years with a genuine Christian man of faith, hope and love. I am truly blessed. Thank you for remembering Mike in such a thoughtful manner.

Mike's decision to continue treatment when the wisdom of those who cared about him was that he should stay home on hospice illustrates how data driven decisions are not always optimal. He could not realistically hope to beat the cancer and the effects of the treatment could be expected to cause discomfort in the final days of his life. That was our wisdom but he discerned something different and gained years of quality life because of it. The last time I saw Mike was at a concert to raise money for a local charity. He was symptom free and told me there was no evidence of the cancer. Even though it reappeared soon after that, his life was more complete because he went against the odds and chose for himself how to respond to his situation.

In his book on leadership, *A Failure of Nerve: Leadership in the Age of the Quick Fix*, Friedman illustrates how too much data can lead to poor decision making. He begins his discussion of the role of data in leadership with health because the "thinking involved

in how anyone ‘manages’ his or her own health encapsulates all critical issues of management.”⁶⁶ Over reliance on data by clinicians contributes to the medicalization of illness by ultimately turning patients into data, much as Donne described himself as being turned into a map. “When life crises are viewed in terms of proportional or systems thinking rather than straight-line, linear thinking, then outcomes other than mere capitulation or escape become possible.”⁶⁷ Patients like Mike resist the algorithmic approach to decision making with resiliency and self-determination. Friedman describes this as integrity or wholeness which allows leaders to be more responsible for their emotional wellbeing and for their own destinies.⁶⁸ Applied to patients, it suggests the ability to resist making decisions which are strictly data driven. For patients who are formed in their faith and supported by the active involvement of their parish and clergy, it means openness to the work of the Holy Spirit. As with Mike, individuals are empowered to discern through prayer what is right. The right course for an individual may not be the same as what is statistically demonstrated to be the one with the most probable best outcome.

Friedman’s account of his own experience as a patient is informative. He began to experience two different sets of physical symptoms, each indicating the need for surgery. He had severe angina with intense physical exertion and he had a recurring tingling and numbness in his left leg and arm. Tests revealed the symptoms were due to a clogged coronary artery and an occluded carotid artery respectively. He had to decide which operation to have first knowing that either procedure would jeopardize his life because of

⁶⁶ Edwin H. Friedman, *A Failure of Nerve: Leadership in the Age of the Quick Fix* (Seabury, 1999), 100.

⁶⁷ Friedman, 154.

⁶⁸ Friedman, 157.

the stress it placed on the other organ. He was at risk of a stroke with one and a heart attack with the other.⁶⁹ Ultimately he had the carotid endarterectomy first. In his telling of this story from the perspective of a patient he illustrates how patients should not let the fact that experts know more rob them of their responsibility to be decisive and, through it all, to manage their anxiety.

Advances in healthcare have resulted in longer lives for those who have access but the objectification of the sick is no better than when Donne compared himself to a two dimensional map. Rather than being daunted by the realities of our healthcare system, parish clergy can make a difference one soul at a time. A final case narrative illustrates how.

Janie had been a resident in an Assisted Living Facility within walking distance of the church for more than a year and she was an Episcopalian. She was quiet and reflective. I was not sure if this was her nature or if it was a learned behavior. She had been in an abusive relationship with the father of her son and had turned to alcohol to cope. She also had a daughter from a second, later marriage. That marriage failed because of her drinking. Her daughter grew up relating to her step-mother more than Janie. There was residual anger on her daughter's part that after all Janie had put her through, now she was a burden. Janie's son was as gregarious as his mother was shy. He was an active Episcopalian in a nearby parish. He was a talented musician who played guitar and sang. Cursillo had been a wonderful experience for him. He considered this his vocation and held a secular job only for subsistence. His love of the Church, outgoing personality and strong belief that with God all things are possible had inspired Janie. She felt that if her son could be such a strong Christian, she must have done something right.

⁶⁹ Friedman, 234.

She was received into the Episcopal Church and stopping drinking when she was about fifty years old. Her daughter and son-in-law were very involved in a large Baptist congregation.

I took communion to Janie in the Assisted Living Facility and enjoyed visiting with her. When her son came to visit his mother, he made a point of visiting me and attending the mid-week Eucharist. He always returned to his home parish on Sunday. The Episcopal Church Women visited Janie and kept her on their prayer list. There were two dark shadows hanging over Janie. First, her daughter tried to conceal it but her anger was palpable. She was suspicious of the Episcopal Church and resentful of her half-brother's happiness. She was jealous of his relationship with their mother. All this bothered Janie. Second, Janie had cancer, squamous cell carcinoma of the soft palate and uvula. She was being treated with radiation but it made her throat hurt too much to eat. She was hospitalized. The hospital based physician did not know Janie but recommended continued radiation and a gastrostomy tube. This would allow her to continue to fight the cancer and receive nutrition directly into her stomach.⁷⁰ At that point the Assisted Living Facility informed her that she would have to move to a facility that provided skilled care.

Janie was not optimistic about being cured and did not want to live with a feeding tube. She was more afraid of treatments for throat cancer, especially surgery, than of dying. She wanted to be able to eat again and to focus on enjoying the relationships she had with her son and the ECW. She also hoped to reconcile with her daughter. Her physician was mystified by her decision not to aggressively fight the cancer. He and I had only one conversation but it seems to have helped because Janie told me on my next visit

⁷⁰Medline Plus, "Feeding Tube Insertion – Gastrostomy," National Institutes of Health, <http://www.nlm.nih.gov/medlineplus/ency/article/002937.htm> (accessed January 4, 2012).

that he stopped pressing her to continue treatment afterward. He referred her to a hospice owned by a publically traded company headquartered in Ohio with nursing homes, home health agencies and hospices throughout the country. When Janie had talked to me about dying, I told her that when the time came she should choose the only local, not-for-profit hospice serving our community. Not only was it locally owned but it was the only hospice with an inpatient unit staffed by their own employees. The discharge planner was surprised that Janie knew her options but the order was changed.

During the time all this was happening, her daughter, Susan, gave me a call. She wanted to know what I had told her mother to convince her to stop treatments and die. She asked why I would give alcohol to an alcoholic and whether I knew how much pain her drinking had caused her family. Her barrage of accusations continued until I took advantage of a pause to tell her about the importance of communion for her mother and I told her that Janie always insisted on receiving only the bread. Susan calmed down when she heard that. She started to cry and apologize for her anger. I reassured her. After that we had a number of very good conversations. When her mother died, Susan gave me one of the most wonderful compliments I ever received. She thanked me for helping her mother, for being patient with her and then added that her husband had said I was the essence of what a priest should be. They were still skeptical of Episcopalians and did not understand sacramental theology but they had come to respect the parish and me for our pastoral care of her mother and, more important, they had come to understand her mother better.

Conclusion

Healthcare is paradoxical. Hope for survival as a human being means subjecting oneself to inhuman treatment. Death is our common fate. If life were a diagnosis, it would have a 100% mortality rate. This is another paradox; to live is to die. When considering death, we turn to poetry but we meet death via the healthcare industry that is built on prose. Clinicians speak in algorithms and outcomes. Suffering is measured as morbidity and death as mortality. So clergy should be most at home in clinical settings because more than any clinician, we are at home with paradox. The very act of bringing the ancient prayers into a modern intensive care unit is paradoxical. Making the sign of the cross over a patient while speaking words of healing and hope, is paradoxical. At the core of the Christian faith is one who suffered and died, was utterly defeated and humiliated, yet lives and reigns.

Parish clergy need not be daunted by the realities of the healthcare system or defeated by its clinical culture, language, social strata and rules. The key to becoming effective in clinical settings and integral to the care of sick parishioners is intentionality, information and focus, one soul at a time. To do this effectively clergy must be confident in his or her role, and respectful of clinicians. Start with the names of sick parishioners on the parish prayer list. Divide them into episodic, chronic and terminal illnesses. My parish is illustrative. We have a parishioner who is recuperating from an infection secondary to orthopedic surgery. Another has recently started dialysis. A third has Stage IV breast cancer. These illnesses respectively are episodic, chronic and terminal. There are practical ways parish clergy can be integral and most helpful in each situation if he or she is informed, involved and helpful.

To be informed does not mean to compete with clinicians. It means to become an informed consumer of healthcare. In the case of a sick parishioner, clergy can act as a dispassionate family member. Clergy are part of the Christian family but are not, and should not be, too invested emotionally in the family system. Practical ways to be a good consumer of healthcare and an effective advocate for sick parishioners include a basic understanding of Medicare, palliative care, and the specific illnesses encountered in ones ministry. Reliable information about Medicare can be obtained directly from the Center for Medicare and Medicaid at www.cms.gov. For palliative care, refer to The Center to Advance Palliative Care, www.capc.org. And, to learn more about a specific diagnosis search for that diagnosis at the National Institutes for Health website, www.nih.gov. Use information gained to ask informed, relevant questions rather than to give advice.

Some episodic illnesses are quickly resolved. Others can be life changing events. In the case of the infection following orthopedic surgery, the parishioner was very sick for several weeks. The initial surgery was considered successful and he was discharged home with a plan for physical therapy. When he started feeling sick and feverish, he had to be re-admitted for treatment of a nosocomial infection, i.e. an infection he acquired in the hospital. He needed intravenous antibiotics for six weeks. He would have had to go to a nursing home for rehabilitation if his wife were not able to care for him with Home Health. Clergy need to have a basic understanding of infection control. Many infections are acquired in a clinical setting from improperly cleaned equipment or from staff who do not use adequate precautions between patients, especially hand washing. Other infections are acquired from the community. To safeguard against clergy putting a patient at risk, he or she should wash up before and after visiting sick parishioners. A parishioner

dealing with a virulent infection may feel too tired to attend parish activities and may be cautioned to avoid crowds. This can lead to isolation, frustration at an unexpected complication to their recuperation, and anger at the hospital for not being clean enough. Clergy can help episodically sick parishioners ask what they can learn from their experience and how they can grow spiritually.

Unlike an episodic illness, a chronic condition is life changing. A parishioner who gets sick and goes to a clinic or emergency room expecting to be treated and recover sometimes finds the illness is a symptom of a condition that cannot be cured. Diagnoses of renal failure requiring dialysis or diabetes requiring constant monitoring of blood glucose are examples of such chronic, life changing conditions. Clergy should lead their congregations in asking how they can be supportive of these families. Chances are the clinicians involved will be focused on medical interventions, pay sources, and education about what to expect from the disease. It will be up to the clergy to consider what impact the diagnosis has on family members and whether the chronically ill parishioner somehow blames himself or herself and considers the illness a punishment.

People find their illness is terminal in various ways. It can be a shocking diagnosis. On the other hand, it can be after a long, exhausting illness. In either case, hospice can be a resource. However, clergy should know that hospice is a very competitive and well financed industry. Parishioners referred to hospice have the choice of choosing which hospice to elect based on their preferences and the services provided by the hospice. Important questions for a hospice include whether it is locally owned or is part of a large corporation; whether the hospice is non-profit; and the outcome of any state and federal complaint surveys.

A parish priest or deacon becomes a clinician when he or she advocates for the sick and their families; fights isolation through sacramental visits and involving the congregation; and, accompanies the sick in praying for the sanctification of illness so “that the sense of his or her weakness may add strength to his or her faith and seriousness to repentance.”⁷¹

⁷¹ *The Book of Common Prayer*, 460.

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The Priest as Clinician: A Case for Intentional and Informed Involvement of Parish Clergy with
Clinical Teams Caring for Parishioners

by

Joe Kimbell Dunagan.

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“The Priest as Clinician: A Case for Intentional and Informed Involvement of Parish Clergy with Clinical Teams Caring for Parishioners”

JOE KIMBELL DUNAGAN

Project under the direction of Professor Robert D. Hughes, III

A challenge for parish clergy is to minister to parishioners as they experience illnesses in such a way as to help transform the experience of being sick from one of objectification and isolation, to an experience that can be interpreted as part of their spiritual journeys. This thesis illustrates how barriers to spiritual care of parishioners during times of illness can be breached and parish priests can become full participants in the healthcare team. To be integral in the delivery of care, clergy must be intentional and informed.

Narratives of persons confronting illness while being objectified and isolated by the healthcare system are utilized to illustrate this thesis. These stories include early seventeenth century Anglican priest and metaphysical poet, John Donne; Sue Baier, who wrote about her experience of being paralyzed for weeks in a modern intensive care unit; the main character in Margaret Edson’s play about a Donne scholar with terminal cancer; and, stories adapted from the author’s ministry.

The divergent understanding of spirituality is problematic, but there is agreement among clergy and clinicians that spirituality understood in some fashion is important. This common ground can be an entry point for parish clergy who seek opportunities to interact with clinicians.

The *medicalization* of illness occurs when clinicians focus on treating the disease, i.e. curing or changing the course of the illness. This treatment is typically data driven, algorithmic and influenced by costs. With clergy involvement, all healthcare can be

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