

Living Hope

A Theological Analysis
by Marie Tulin

Introduction

In this paper I will explore, from the perspective of a hospital chaplain, the experience of hope in the lives of people who have been given a diagnosis of a life-limiting disease. I will discuss how our culture's orientation towards medicine has "medicalized" hope to such a degree that its religious roots, meaning and healing power are difficult to recognize and claim. I will then illustrate how a patient's responses, often expressed in the language of illness and medicine can be understood—translated—into theological images, symbols, and experiences. The pastoral caregiver's ability to facilitate this re-imagining is crucial to the dying patient ability to become a hoping person who can make a transition from the time-limited world of critical illness to a space with a greater horizon.

Historical Notes

Greek philosophy deeply influenced western religion and medicine. The philosophers contemplated and theorized about the human condition, including illness, dying, death and the afterlife. By the 4th century BCE physicians during the Hippocratic era identified three parts to medicine: the disease, the patient and the physician. Previously disease was thought to be a divinely inflicted upon those who had angered the gods. Consequently, the physician was a delegate of the gods, a priest, who facilitated the sufferer's recovery.

Hippocrates, on the other hand, saw disease as a natural entity whose progress and outcome could be prognosticated by the skilled and observant physician (attached picture of Hippocrates taken from historical-studies.ncl.ac.uk/info/events/medicine_history_conference.asp, 1/28/05). Somewhat later, Plato and Aristotle undertook contemplation and argumentation about dying, death and the afterlife. Here Aristotle describes the fear associated with dying:



Fear may be defined as a pain or disturbance due to a mental picture of some destructive or painful evil in the future. Of destructive or painful evils...only such as amount to great pains or losses. And even these, only if they appear not remote but so near as to be imminent: we do not fear things that are a very way off; for instance we all know we shall die, but we are not troubled thereby because death is not close at hand.¹

Paul Carrick identifies four attitudes the Greeks held towards the dying process. It is not difficult to see parallels in our own time:

- (a) The *heroic attitude* where willingness to die is seen as a best test of the highest ideals

¹ Paul Carrick, *Medical Ethics in the Ancient World*. Washington, DC: Georgetown University Press, 2001, 60.

- (b) The *merciful attitude*, in which a quick and easy death (euthanasia) is seen as the best solution to relentless personal suffering
- (c) The *Aristotelian attitude*, according to which the personal cultivation of courage is the best psychological and moral remedy for meeting death
- (d) The *Epicurean attitude* in which fears of death can be eliminated by recognizing that these fears are baseless and illusory.²

These “attitudes” are informed by a sense of duty to demonstrate an appropriate attitude towards death. The emotions around death are expressed indirectly by how one might face death. Yet the preceding paragraph illustrates Aristotle understood “fear” as normal, if not the norm.

Not much has changed. We may have an idea of how we wish to face death, we hope we will do it, but in reality our emotions are often not bound by our intentions. We recognize our hope is conditional, and conditioned upon factors not within our control.

Hope in the Judeo-Christian Tradition



Hope’s foundation in the Judeo-Christian tradition is rooted in the character of God, creator and redeemer of the universe. Hope in the Hebrew Bible is connected to God and God’s favor towards the Jewish people as demonstrated in God’s covenant with them and fulfillment of it.³

The followers of Jesus perceived further revelation about the nature of God through Jesus. From scriptures we learn that God’s nature is self-giving love, steadfastness, forgiving, creative and creating and redeeming.⁴ Paul speaks of hope as “an anchor for the soul” (Hebrews 6:19-20), and in 1 Peter 1:13 we are told to “Set your hope perfectly on the grace that is to be unto you at the revelation of Jesus Christ.” We should keep in mind the words “anchor” and “grace” as qualities of spiritual peace. (Attached picture of a statue of St. Paul taken from www.christusrex.org/www1/citta/B-Piazza.html, 1/28/05).

A Physician’s Promise

For centuries humans beseeched gods or God to heal their sicknesses. Today the majorities of people who have access to western medicine seek their physicians first and appeal to God later. In illness the orientation of hope has shifted from God to humans (physicians) or for some, to chance. Sherwin Nuland addresses hope from a physician’s point of view and describes what “every doctor knows” about hope beyond the data, its interpretation, diagnosis and prognosis:

² *Ibid.*, 64

³ Andrew D. Lester, *Hope in Pastoral Counseling*. Louisville, KY: Westminster John Knox Press, 1995, 66

⁴ *Ibid.*

[There is] a single theme interwoven into the education of all medical students and verified in the crucible of daily experience, it is the unstated precept that hope is the subtext of every encounter that a doctor will ever have with a fellow human being who is sick. People come to us seeking hope, and we are meant to convey hope in every facial expression and clinical intervention that we undertake. Hope is a powerful element in the therapeutic arsenal. Almost always, it is synonymous with a reassuring optimism that we can do something to fend off the depredations of disease.⁵

But what does hope consist of when there is no optimism for cure or lengthening of life? In this case “hope is to be imbued with the expectation of a good that is yet to be...not in remission...[but] other places awaiting discovery.” These hopeful forms are a

spoken or unspoken promise that this man or woman who puts such trust in us will not be abandoned to die alone, that the meaning of life soon to end will be perpetuated within our memories and our actions; and that insofar as this can be managed no suffering will disturb the tranquility of the final days. Of these three forms of hope only the last is not always possible to fulfill.⁶

Nuland suggests this is the covenant he and other physicians enter into with dying patients. Most assuredly, this statement is meant to describe the highest standard of compassionate medical care, but its faith in human institutions and human nature is, one might say, nearly idolatrous. It can be argued that these promises are so sacred and so difficult to keep that only God could honor them.

Aspects of Hope

Words found in the dictionary and thesaurus that describe hope include conviction, trust, promise, confidence, assurance, anticipation and conviction. Theologian David Woodyard describes the “attitude and potential of hope.” He writes that what is “most authentic about [human beings] is the disposition to hope, to live from the future rather than in terms of the past and present. In hoping, [humanity] reaches beyond every apparent limit with anticipation, inquiry, and vision...”⁷

Andrew Lester compares two useful concepts of hope: finite and transfinite. Finite hope is the term for expectation about a goal attainment, i.e., “I hope this chemotherapy works.” Transfinite hope, on the other hand, describes hope “that is placed in subjects and processes that go beyond physiological sensing and the material world”⁸ Imagining an open-ended future is basic to maintaining hope. When Lester writes, “transfinite hope embraces the mystery and excitement of open-ended future and the not-yet,” he is describing what is at the root of the spiritual experience.⁹ Hope’s future story is one that is different than the one experienced now.

Medicine also looks to the future in curing illness and conquering disease. In terminal illness, however, hope as “cure” and hope as a “different future” are often conflated. Nuland speaks to this:

⁵ Nuland, *The New Republic* on line

⁶ *Ibid.*

⁷ Woodyard, 34 as quoted in Lester, 62.

⁸ Lester, 62

⁹ *Ibid.*, 69

I would argue that of the many kinds of hope a doctor could help his patient find at the very end of life, the one that encompasses all the rest is the belief that one final success may yet be achieved whose promise vanquishes the immediacy of suffering and sorrow. Too often, physicians misunderstand the ingredients of hope, thinking it refers only to cure or remission. They feel it necessary to transmit to a cancer-ridden patient, by inference if not by actual statement, the erroneous message that it is still possible to attain months or years of symptom-free life.¹⁰

Nuland is criticizing false hope, as hope for a quality of life or lifespan, which no one can promise a terminally ill patient with certainty. This is complex problem, for most physicians are as uncomfortable as the rest of us in admitting their limitations, the limitations of their art, and talking about death. Nuland believes physicians “manifest the entire society’s current refusal to admit the existence of death’s power and perhaps even death itself.”¹¹

And so it often falls to the hospital chaplain to help the dying patient move from hopelessness to hoping. She does this by seeking out a life story that is different from the often-told medical history. This story is the patient’s narrative of his life story. This story has a past, a present and future. It is the identification, holding onto, the honoring of the new future story that is not tethered to the body’s finitude. Good pastoral care helps the patient rediscover and sustain that story in order that the patient can redefine his life *on* his terms, not solely *in* the terms of his disease or its expected outcome. (Attached picture taken from



http://www.efca.org/chaplains/media/hospital_chaplain.jpg, 1/28/05).

In theological terms, we are interested in the patient’s narrative theology and his eschatological beliefs. What are the implications of his disease to his “future story”, what will be left undone and incomplete, what can be begun, experience, even complete in the finite time left to him? How might that future narrative be re-imagined and enacted so that there is a sensed or actual “culmination” to life, and a sense of continuation of one’s life after death.

Two Case Studies

These are very modest cases. I could have told other stories that were longer, more complex and perhaps better illustrated my skills as a chaplain. But these stories stuck with me. I remember something from every story told by a dying person. The fact that their words, like their days, are numbered makes one pay attention. Also, people who have a terminal illness and who are in the hospital usually don’t have much energy for conversation. However, as I relate these stories I am struck by the content of what was unsaid, the subtext. Even what is unsaid can have significance. I have some reservations about my assuming responsibility for interpreting the theological content. Because these are their words, and I cannot not ask them if my interpretation is correct, I feel compelled to affirm that theology, like hoping, is work of the imagination.

Michael: A Story of Loss

¹⁰ Nuland, *How We Die*, p223.

¹¹ *Ibid*, 223

In response to my greeting and inquiry about how he is doing, the patient whose name is Michael, answers:

Patient: O.K. I guess. You know, I have melanoma; I only have about 6 months to live.

Chaplain: (remains quiet)

P: But, that's o.k. I'm ready to go. I'm at peace.

C: How is that?

P: I've had a good life, a wonderful wife and kids who've turned out ok. I enjoyed my work. I'm leaving my wife enough to be comfortable; my affairs are in order.

C: So you feel like you've settled your affairs. What about your faith? I see you are Catholic. (I know this from the census)

P: I never go to church! I haven't been since the priests did those terrible things. How could anyone do those things to a kid? I want nothing to do with them, nothing!

C: I'm sorry. This whole scandal has been so painful to so many people. What about the sacraments....

P: I haven't had communion in a year. They took my church away from me.

In the secular world, Michael is a man who is prepared for his death. His business affairs are in order, and his wife is well provided for. But he has suffered significant spiritual losses. At the time he needs it most, his church, the House of God, has polluted itself in sexual scandals. Priests, who in the Catholic tradition are in the line of descendents of the apostles, have violated their priestly vows. The representatives of God are spiritually unfit and unavailable to help him in his time of greatest need.

I inferred he was a faithful Catholic if he took Communion until a year ago. The sacrament of Communion in the Catholic Church is not a "remembrance" of Jesus' last supper; through transubstantiation the people partake of the body and blood of Christ. As often as they receive Communion they share not only in the Lord's Supper, but also in Christ himself. Holy Communion is the centerpiece of Catholic worship; it is the central event of every Mass. To deprive oneself of Communion, or to feel oneself deprived of it could be wrenching experience.

Michael had a strong need to control the circumstances of his death; he talked at length about his advance directives and how he wanted his wishes honored. We stayed on this subject in part because I had a further suggestion, and that gave him even more reassurance. Advance directives have theological significance. They are legal papers (witnessed and notarized) specifying what a hospital may or may not do in case of a life-threatening medical emergency. The individual may specify whether or not they want CPR, intubation, or to be put on a respirator. One may also specify whether they should

receive fluids and/or food, and how they should be given. In other words, these are instructions to health care providers about how hard death should be fought off. Will God's will be done in God's time?

One may also specify how much medication to control pain should be administered. Although the Church opposes euthanasia for any reason, in the case of *unremitting* pain and suffering and when there is *no* reasonable hope of recovery, a sufficient amount of medicine may be given to control the pain, even if it results in the patient's death. (In medical ethics this is called the double effect.) If the intention is not to kill the patient, but provision of pain relief, then "natural law" which is a significant tenet of Catholic theology, has been observed.

Where was Michael's hope? From our conversation, he hoped to control how his life ended. I could have explored more. Could he imagine any circumstances where his hope in the church might be restored? Could he hope to find a priest he trusted? What does it mean if one's trust in an entire institution can be destroyed by the acts of a few? Did he equate "church" and "priesthood" with God? Is his trust in God shaken? Destroyed? If so, could he imagine how he might re-establish a relationship with God? Does he want to? Why or why not?

It is a fact that a chaplain's contact with many patients is very brief. Often there is only one chance to speak with the patient before he or she is discharged. Sometimes the best you can hope for is to leave them re-evaluating their assumptions.

Barbara: A Study in Agape

Learning that one has a life-limiting illness is a crisis that precipitates other crises. Barbara had radical surgery for metastasized bowel cancer. The operation saved her life, but left her with no digestive tract and a life expectancy of about four months. When I met her she was weeping. She had awakened from her surgery and had been given the news. She said, "I can't ever eat again. I love to cook. How can I cook for my husband and son and never taste food again? Oh, oh, this means I can't take Communion again, ever." (Attached picture taken from http://www.presentationofmary.com/Province/provincial_ministries.htm, 1/28/05).



Between the time Barbara was anesthetized and the time she woke up, her life had changed. She became separated forever from two intimate parts of her present and future story: sharing meals with her family and sharing a meal with God through the body of Christ. I too had a hard time contemplating the fact that she could not eat such a tiny thing as a Communion wafer. She looked at me and asked, "What would you do?" I answered "I've never faced what you are facing, but I can tell you the hardest thing for people left behind is unfinished business: things that need to be said, relationships to need of healing..." She nodded.

I was speaking from some experience but no conscious theological understanding. I see there was theological content in the response. I was challenging her to take part in the time left to participate and facilitate healing. The implicit understanding is that others go on living, and our relationships live on after us. In this way, we live on too. In this critical moment, she had some reason to look beyond her physical impairment and do some "soul work" that could last beyond her earthly years. Barbara did not deny the reality I implied by my words "people left behind" but was able in the moment to look

into a future, which did not include her body but her works. Her story also opened up the possibility of a fresh understanding of the Christian sacred story where Jesus moves from life to death and to life again, and his promise of the same to humankind.

For Barbara food and family and the Host taken in communion with her faith family represent “community”. This illustrates a central point about hope: “hope is communal and relational, not isolationist and separatist.”¹² Barbara alluded to her husband as a “big baby,” who was emotionally needy and depended too much on her. We did not discuss this much. However, when I looked at her medical chart later I read the social work report about a meeting that took place after I saw her. It said in part “Barbara expressed her concern about the relationship between her husband and son and her wish that they work out their differences...” It strikes me that this is about “saying what needs to be said, relationships in need of healing.”

She was active in her hoping for family reconciliation, and actively initiated a conversation that might bring it about. I had no idea that my answer struck a deep cord about her worries for the future. It may have been chance; it may have been the Spirit of God. In my conversation the word “hope” was never used. But hope was turned into an active verb. Until I wrote this brief case the “hoping” was not visible to me. Undoubtedly, Barbara has died; without a doubt she lives on.

Conclusion

Feminist theology provides a powerful framework for pastoral care. As Ann Carr writes,

Feminist theology has been ecumenical from its origins, as discussion has included Christians of many denominations, Jewish feminists, and feminists from other traditions or of no tradition at all...The wide ranging use of source materials and interpretative strategies has resulted in a diversity of feminist theological approaches, so that it is more accurate to speak of feminist theologies...¹³

An open approach, as modeled by the above statement, allows the pastoral caregiver to engage a patient on the patient’s own terms, in the context of the patient’s own history/narrative which may be “Christian, Jewish, another tradition, or no tradition at all.”

Mary Catherine Hilkert describes a theology of revelation that is “relational, dialogical and experiential.”¹⁴ This describes exactly the non-dogmatic theological framework that I believe a pastoral caregiver uses to engage a patient at the end of life in creative reflection that may elicit a re-visioning of hope. It is relational because one cannot hope alone, in isolation, and outside communion with another, which occurs in dialogue with another. It is experiential because it must come from the embodied experience of the patient. The experience of the patient is the story the chaplain attends to, and with the patient builds upon, extrapolates from and uses to look to the future, no matter how short.

¹² Gerkin, pp.247-248

¹³ Ann E. Carr, 64, in *Freeing Theology: The Essentials of Theology in Feminist Perspective*, ed. Catherine Mowry LaCugna. San Francisco: HarperSanFrancisco, 1993.

¹⁴ Mary Catherine Hilkert, as quoted in *Freeing Theology*, 64.