

4-16-2010

## Shamanism, Spiritual Transformation and the Ethical Obligations of the Dying Person: A Narrative Approach

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Shamanism, Spiritual Transformation and the Ethical  
Obligations of the Dying Person:  
A Narrative Approach

by

Ellen W. Klein

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
Department of Religious Studies  
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Date of Approval:  
April 16, 2010

Keywords: Ethics, Illness, Spirituality, Relationality, Religion

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### Dedication

For Dr. Fasching whose constant and generous expressions of grace  
are a mirror for me of the steadfast love of God.

And

As with all things, for my Avigayil who teaches me the great joy of  
responsibility.

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ABSTRACT

The person experiencing chronic or protracted illness is confronted with a complex array of physical, emotional and spiritual trials. This thesis explores how chronic illness can be viewed through the lens of the shamanic experience of dismemberment and re-memberment and shows how clinical, narrative, and relational models on their own are insufficient to speak meaningfully to illness experiences, but the integration of aspects of each of these models when coupled with shamanic initiation experience creates an innovative model for patients and those with whom they are in relationship.

## Introduction

Narratives aren't just the stories we tell our children at night. They are the stories we tell ourselves, the stories that help us make sense out of and find meaning in our experiences. They are also the stories we tell others in cathartic efforts to externally order moments of internal chaos and communicate who and what we are becoming as a result of our experiences. Illness in particular has the ability to disrupt the life story but as Arthur Frank in his work *The Wounded Storyteller* suggests, "the ill person who turns illness into story transforms fate into experience" (xi). But what kind of story can the chronically ill person tell that will fully and meaningfully articulate the experience of dying slowly through a series of seemingly endless exacerbations and reprieves? What story can the chronically ill body tell that has the power of spiritual transformation even in the face of death?

One of the earliest known genres of stories in which illness becomes a vehicle for spiritual transformation is that of the shaman found originally in tribal societies among the peoples of Siberia and Manchuria. At the roots of medicine, religion, and the hero's journey, Shamanism has made a significant historical contribution across

cultures to the human experience. At some point in life each person experiences a failure or crisis of some sort and, for this reason, the initiation experience, according to Mircea Eliade in his work *Rites and Symbols of Initiation* "lies at the core of any genuine human life" (135). The shaman's initiation experience represents a kind of spiritual death and rebirth, acting as an ancient rite of passage marking transition from one state of being to another, from the novice to the initiated. The passage from childhood to adulthood, for example, is a natural transition recognized in many cultures even today. The shaman's initiation is something more than developmental transition, however. It is intense, tortuous, even violent and, I will argue, remarkably similar to the experience of the person ravaged by disease.

Mircea Eliade, in his classic work on shamanism, recounts a shaman's spiritual transformation as part of a near death experience brought on by smallpox. During his experience, he leaves his body, enters the realm of spiritual beings, is instructed in the knowledge of plants used in healing and then sees himself being torn apart, his bones strewn everywhere and then collected and put back together again. Life is breathed back into his body and then he is sent back as a healer to his people and awakens in his hut, back in the earthly realm. Through his illness and near death experience, the shaman is torn

apart, re-membered, and ultimately transfigured (Eliade, 1964, pp.38-42). Indeed, he is given three new bones that enable him to heal and communicate between the physical and spiritual realms. Having attained spiritual insight and wisdom through his encounter with death, the shaman is transformed into a healer and spiritual guide, capable for example of leaving his body at will, foretelling the future, healing the sick, and rescuing lost souls. The shaman's initiation experience, I believe, is uniquely suited for the chronically ill as a story through which their wounded bodies can speak. As Frank's work suggests, the fate of illness becomes the experience of spiritual transformation (xi). "The disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability" (Frank, xi).

In this thesis, I will chronicle the ebb and flow of protracted illness as a spiritual process of dismemberment and re-memberment, examining the aspects of responsibility to intimate others. I will argue that the experience of chronic or protracted illness must not be reduced to little more than a clinical event because it is not only a physical but also spiritual process represented best through narratives and understood better as an opportunity for spiritual transformation as described in the shaman's experience through which the sick may discover meaning. My thesis is that in order to fully understand the



nature of the illness experience, we must explore the spiritual dimension. I will argue that the spiritual component of the shaman's initiation experience may provide clues for understanding illness as spiritually transformative even in the absence of physical healing, and that obligation to intimate others is critical to that transformative experience.

I have come to understand my own experience of chronic illness as a mirror of the shaman's spiritual experience of dismemberment and re-memberment. Each relapse is a death. The succession of relapses is felt like a series of tiny deaths, and in those moments of crisis, the physical and emotional despair is so keen that death would be a welcome release. Yet my feeling of obligation to others who care about me and about whom I care will not let me give up. To abandon my relationships and the obligations embedded in them would be to relinquish a critical part of what it means to be human. The face of my daughter appears before eyes squeezed shut in an effort to escape the circumstance in which I find myself. In spite of everything, I am wooed by her, by my commitment to her and my obligation to those others that I love who hold a claim on me as well. My relationships call out to me, their voices the only thing more audible than my despair. Bound by the claim they have on me, spiritual re-memberment begins with that pivotal moment in which what is required of me supersedes

my desire to give up. Like the shaman, I find my experience has the power to transform rather than annihilate.

The following narrative account illustrates a moment of exacerbation in my own experience of chronic illness. At the time, I could not know for certain that I would recover or that, even if I did, I would resemble my former self in any recognizable way.

It is inconceivable that I can have no feeling from the waist down, no appreciable feeling that would allow me to use my limbs, but I have pain, excruciating pain. Remember that I have had a child, experienced the primal pain of labor. Labor has nothing on this. This burns and sears and fires off rounds of electricity from my back, around my torso and down into my legs. It vibrates in concerto with the spasms in my muscles. It does not relent, does not even ebb like the contractions of labor, and worst of all I cannot see hope of birthing something beautiful from this. I am not one brought often to tears for myself, but they stream in hot rivulets down my cheeks and hopelessness begins to take up residence. I do not want to see anyone. I do not want to be seen.

The contingent nature of my disease process leaves me dangling precariously by the thread of "the law of thirds." With each exacerbation, I am confronted with a third of a chance that I will

recover all I have lost physically, some of what I have lost, or none. And with each exacerbation something of my former self is changed emotionally and spiritually. I am never the same person I was before the relapse no matter what I may gain physically. I am not the mother, wife, friend or colleague I was before. I am, whether I want to be or not, changed by my experience. Illness makes an indelible mark on my life.

The person experiencing chronic or protracted illness is confronted with a complex array of physical, emotional and spiritual trials. This thesis will explore how chronic illness can be viewed through the lens of the shamanic experience of dismemberment and re-memberment and show how clinical, narrative, and relational models on their own are insufficient to speak meaningfully to illness experiences, but the integration of aspects of each of these models when coupled with shamanic experience creates an innovative model for patients and those with whom they are in relationship.

## Illness as Clinical Experience

Protracted illness presents a unique problem for patients, caregivers, physicians and ethicists and, in particular, is comprehended most often within a clinically, medically, and physically oriented paradigm. This is evident in the current scholarly debate in which illness is primarily viewed through a clinical lens that focuses on the tension between paternalism and autonomy in medical decision-making. Until the middle of the twentieth century, the emphasis was solely on paternalism but has shifted since then to an equally radical focus on autonomy. The emphasis on absolute autonomy in medical decision-making however has resulted in an over emphasis on patient rights that communicates a problematic degree of personal freedom and subsequently ignores the experience and expertise of clinicians.

Two voices are most prominent in this debate. Robert Veatch and Edmund Pellegrino arguably represent the most noted and respected scholarship in medical ethics. While Veatch more strongly represents the sentiments of autonomy and Pellegrino aspects of paternalism, both have shifted their approach to the fulcrum between the two extremes and make the case for the benefits of representing elements of each in the medical ethical aspect of the illness

experience. The danger of focusing on one to the exclusion of the other is the potential for an imbalance in decision-making power. Paternalism unchecked by patient autonomy has the power to override self-determination or personal narrative, rendering medical decisions that may lack relevance for the patient. While incorporating the experience and expertise of the practitioner, absolute paternalism risks dictating clinical outcomes that lack language sufficient to communicate hopefulness or reasoning that would inspire patient compliance. This kind of paternalism risks excluding the patient from the process and may therefore, do more harm than good.

The risks of absolute autonomy carry equal weight. Placing decision-making entirely in the hands of patients disregards the experience and expertise brought by practitioners to the process. In the same way that paternalism exercised in its absolute form by practitioners through clinical decision-making may unwittingly excuse patients from the work and responsibilities that are a natural part of being human, autonomy risks outcomes in which the patient may excuse him or herself, thereby ceding to the disease process crucial aspects of personhood. As a result, the illness rather than the person with the illness takes center stage.

Although they once were at nearly opposite ends of the spectrum, Robert Veatch and Edward Pellegrino have come to balance

the strengths and weaknesses of paternalism and autonomy by using virtue ethics and the ethic of beneficence as complementary mediators between the two extremes. What they bring to the problem is balance to the potential harm of absolute forms of both models.

Speaking to the need for this balance, Robert Veatch offers an alternative to the heavy handed medical paternalism born out of the Hippocratic tradition in which the patient and the patient's friends and family are deemed ignorant because they do "not have the knowledge that comes [for physicians] with initiation into the cult [of medicine]" (Veatch, 59). "The Hippocratic Oath instructs the clinician, whether using his own personal judgment or that of peers, to do what appears to benefit the patient-even if the patient is not in agreement or does not want the offered benefit" (Veatch, 58). Here Veatch aptly articulates the root problem with forms of absolute paternalism in that it makes no room for the concerns of the individual patient, denying elements of personal agency. Subsequently, the patient treated under paternalism is confined to a passive, receptive role and denied active participation in his or her own care.

Veatch points out in his work *The Basics of Bioethics* that action and intent are key concerns in the recent history of medical ethical decision making. He weighs the differences in normative ethics between emphasis on beneficence (producing good outcomes) and

nonmaleficence (avoiding bad outcomes) in value theory and the emphasis on benevolence (willing to do the good) seen in virtue theory (Veatch, 6). The physician acting paternalistically under the auspices of good intent, while benevolent (willing the good) may not have actually been beneficent (doing the good) (Veatch, 7). This is seen, for example, in the physician who avoids truth telling in order to avert potential harm to a patient by causing distress. Since the late 1980's, a "return to the more traditional interest in the virtuous character of the health provider" has emerged (Veatch, 7). Virtue ethics would concern itself with the physician's character and his motive or intent in choosing to avoid truth telling with a patient, whereas, value theory would focus solely on the physician's actions, specifically, does the physician's lie avoid a harmful outcome for the patient. More specifically, the concern is that this paternalistic good intent would produce actions that override the aspect of patient autonomy understood as the respect for persons (Veatch, 7). Fortunately, a more recent emphasis has been placed on accounting for both the actions and character of the physician. This is indicative of the move in medical ethics towards balance between the earlier extremes of each ethical model and also between individual values of the patient and physician.

Although “autonomous reason [has come to function as] the cornerstone of secular bioethics,” Edmund Pellegrino does not support patient autonomy as the primary concern of medical ethical decision making (Pellegrino, 140). Even though an ethical perspective based purely on autonomy is in direct opposition to the Roman Catholic religious paradigm that dictates his understanding of the sanctity of life, he could certainly not be accused of advocating for absolute paternalism either. While Catholicism, he admits, “often is at the most extreme pole from the current antimetaphysical biases of contemporary bioethics,” he does not advocate for dismissing the concerns of individual patients (Pellegrino, 141). He does this to the extent that he believes the job of the clinician healer is to cure when possible and to provide hope to patients in despair but not to the extent that their “compassion...sanction[s] killing the suffering person or helping him to kill himself” (Pellegrino, 121). For Pellegrino there are clearly limits to the degree of autonomy patients should be afforded. Rejecting purely autonomous actions such as euthanasia and assisted suicide, Pellegrino calls for clinicians to become “expert[s] in palliative care...help[ing] each patient to understand the roots of his suffering and try compassionately to remove them” (Pellegrino, 124). Like Veatch, he is as interested in the physician’s character as his or



her actions. Pellegrino summarizes his conception of virtue in ethics in the following:

“Beneficence would be more than nonmaleficence, more than avoiding harm or even doing good. It means doing good even when it means sacrifice of self-interest. Autonomy would focus on respect for persons and their dignity as creatures, not on some absolute freedom or license to do with our lives what we please. Respect for persons would, indeed, emphasize self-governing decision making. But our freedom as creatures of God is always within the constraints of ethical and moral determinants derived from Scripture, tradition, church teaching, and the study of ethics (Pellegrino, 1988, 122-123).

Pellegrino does something here that Veatch does not. He offers a very personal definition of what it means for the physician to be virtuous and the kind of character from which one should expect a physician’s actions to be informed.

In *The Virtuous Physician and the Ethics of Medicine* Pellegrino examines the impact of virtue ethics when applied to the role of the physician. He notes a need for balance between action and character or intent similar to what is found in Veatch’s work.

The more we yearn for ethical sensitivity, the less we lean on rights, duties, rules, and principles, and the more we lean on the

character traits of the moral agent. Paradoxically, without rules, rights, and duties specifically spelled out, we cannot predict what form a particular person's expression of virtue will take. In a pluralistic society, we need laws, rules, and principles to assure dependable minimum level of moral conduct. But that minimum level is insufficient in the complex and often unpredictable circumstances of decision-making, where technical and value desiderata intersect so inextricably (Arras and Steinbock, 82-83).

For Pellegrino, ethics based in virtue must accompany virtue based in rights or law. Perhaps more importantly, Pellegrino and his colleague David Thomasma in their book *For the Patient's Good: the Restoration of Beneficence in Healthcare* advocate for what they term "beneficence-in-trust". Here the concept of beneficence is re-interpreted to function in the patient /practitioner relationship in such a way that patient autonomy compliments rather than competes with the practitioner doing the clinical good. The relationship is defined by an element of trust between the parties that each will act in the best interests of the other. This, I believe, is what Pellegrino is talking about when, as noted earlier, he says, "[beneficence] is doing good even when it means sacrifice of self interest" (Pellegrino, 1988, 122). Through dialogue, both practitioner and patient express their wishes

and/or concerns and come to understand one another's unique contribution to the shared decision-making process. A terminal patient, for example, may come to understand the benefit of an undesired treatment as a means of decreasing pain or a physician may come to accept a patient's desire to discontinue a treatment not in keeping with their values. In this way, a patient's autonomy can be expressed without leaving the patient abandoned in the process, or allowing the practitioner to run roughshod over the patient in a radical act of paternalism. Along with Veatch, Pellegrino and Thomasma wisely advocate for a combination of compassionate and pragmatic ethical approaches rather than one that takes precedence over or claims no use for the other.

While issues concerning paternalism and autonomy, and value and virtue ethics are only a small part of the complex processes of medical ethical decision making, my intent here is not to detail the many facets of the medical model but rather to point out its major focus and highlight the fact that even at its most intricate, the model is still not enough. The balance Robert Veatch and Edmund Pellegrino bring to the historical tendency in bioethics towards extremes in the ethics of paternalism and autonomy is crucial for both patients and practitioners but the danger remains in focusing solely on any of these clinical aspects in that alone they are insufficient to speak to the full

range of concerns for patients who are not ever simply a disease to be managed or clinical outcome to be effected. Even Veatch notes “[physical] health is an important goal, but not the only one” (51). As such, the purely clinical story, however canonical, does not have the ability to represent the full experience of illness.

## Illness as Narrative Experience

“Human life is storied life” (Bochner, 73). In order to understand and find meaning in our experiences, we live our lives in the context of story, the stories we tell ourselves, and the stories we tell others. Darrell Fasching, in his book *Comparative Religious Ethics*, explains the rich history of storytelling as a means by which to understand and express meaning found in the full range of human experience.

Life, it has been said, is just a bowl full of stories. As far back as we can see into the misty recesses of time and the human adventure, human beings have been not only storytellers but story dwellers. Their stories coursed through their veins and sinews and came to expression in song and dance. To this very day human beings see and understand the world through the lenses of their stories (Fasching, 10).

Because we are not clinical beings, but individuals living inside a story, illness experiences examined through narrative are understood holistically and in greater detail. Illness is a kind of chaos that disrupts our story as we have come to understand it and furthermore disrupts our understanding of who we are in that story. Our lives are

interrupted as a consequence of the disruption of our sense of self, and who we are or are becoming must be reinterpreted, rewritten. If medicine is to treat the whole person, it must have the whole story. For this reason, including the narrative aspect of the individual is crucial to understanding the problem of illness. This aspect is what the clinical model, despite its many practical and philosophical attributes, lacks. Rita Charon, a physician, recognized the limits of the clinical model and the value of incorporating and listening to the stories of patients. By encouraging the inclusion of patient narrative in assessment and treatment, "narrative medicine provides health care professionals with practical wisdom in comprehending what patients endure in illness and what they themselves undergo in the care of the sick" (Charon, vii). Narrative medicine, she says, acts as a "corrective to some of these failings, a support to these emerging strengths, and response to these widespread yearnings...to unify and cohere divergent aspects of sickness and healthcare" (Charon, ix). Having so clearly made the case for thinking narratively about illness as a complement to thinking clinically and as a benefit to both patient and practitioner, she has emerged as an authoritative voice in medicine and medical ethics, especially for clinicians.

As part of listening and thinking narratively, Charon examines the problem illness creates for the body and for the sense of self. The

body, she writes, "is proxy for the self...speaks [for] and can be observed to constitute the self" (Charon, 86). As Charon points out, "the body... coauthors the story of the life being lived in it" (87). "Without the body, the self is an abstraction...cannot be uttered...cannot enter [into] relation with others" (Charon, 87-88). So when illness mars the body, it mars also the self inhabiting the body. The following narrative vignette is drawn from a subsequent exacerbation of illness in which my body was wrecked by dystonia and seizures as a result of a lesion on the right hemisphere of my brain and illustrates the discord Charon says illness brings to the sense of self.

Staring in the mirror, I do not recognize myself. As if looking in a funhouse mirror, I have become some distorted and grotesque caricature of the person I used to be. I am not this person... this is not me!...the voice of my fading former self pleads inside my head....I don't know who this is staring back at me, but I am angry and frightened by what I see, perhaps more so by what I don't see, an image reflecting the me I know. My face twitches rhythmically wrenching the left side into an ugly smirk. The rest of my left side twitches along with it, my limbs curling in on themselves, twisted and torqued into painful positions from which I cannot extract myself. Ripples of

contractions roll over my abdomen and ribs and around to my back, squeezing me and from my diaphragm producing an animal-like grunt. Perhaps that is what I have become...an animal. Surely there is nothing human about the state I am in now. I wait for each wave to pass and wait more anxiously for the next one to come in its painful wake, wondering if and when it will ever stop.

Here the distortion of body is so great as to produce a distortion in my sense of self. I cannot “see” myself in this body. I don’t want to because the divide is too great between who I know myself to be in bodily form and who I see in the mirror. And so, the story I tell of my self is halted, discombobulated. I am in need of a new story to make sense of the chaos illness has wreaked not only on my body, but on my self. To borrow Charon’s language, my corporeal truth must find a way to become narrative truth. I need my health care providers as clinical partners to see and hear the narrative crisis created by my illness, but I too must recognize and listen to the loss experienced by the self and through the body. To do so is to make room for a new story of body and self to emerge.

Charon’s work skillfully and beautifully weds the practical, clinical demands of practicing medicine with the unfolding stories of patients. Together, all of the benefit of clinical intervention is actualized without



divorcing the patient from personhood. Most importantly, her work advocates for approaching illness holistically and patients as persons not just disease processes to be managed or medical decisions to be made. But for the patient whose life story has become no longer relevant in the context of illness, what kind of story can the body tell?

Arthur Frank brings to the narrative conversation the tales of the “wounded storytellers.” He gives the sick a voice,” not just to work out their own changing identities, but also to guide others who will follow them” (Frank, 17). The wounded as tellers of story shift from passive receivers of care to active givers of care broadening the “circle of shared experience” (Frank, xii). “Because stories can heal, the wounded healer and wounded storyteller are not separate, but are different aspects of the same figure” (Frank, xii). Frank shifts narrative contribution to clinical practice as seen in Charon’s work to narrative ethics as he envisions it: “an ethics of commitment to shaping oneself as a human being” (158). “The personal issue of telling stories about illness is to give voice to the body, so that the changed body can become once again familiar in these stories” (Frank, 2). This is no easy task. For while stories can tell about the body, more is required to “make sense of illness stories... told [and heard] through the diseased body” (Frank, 2-3). Illness stories are not however, only personal. As Frank says, they are also social, for stories are told to

and in relationship with others (3). The very telling of a story, Frank says, implies a listener (3). And so for Frank the questions remain, what kinds of stories can sick bodies tell and what impact does the social context have on their telling?

“Disease interrupts a life, and illness then means living with perpetual interruption” (Frank, 56). Frank looks at the kinds of narratives through which the sick as “wounded storytellers” manage and story the interruption that is illness. He describes three kinds of narratives in which “wounded bodies” are storied: restitution, chaos, and quest. In restitution stories, the sick, least often the chronically ill, seek and regain their health. Chaos narratives are in direct opposition to the restitution narrative, in that they “negate...expectation [and maintain a plot that] imagines life never getting better” (Frank, 97). The quest narrative “meets suffering head on, [with the belief] that something is to be gained through the experience” (Frank, 115). Each of these stories offers a way to navigate towards coherence and make reparation for the damage done by illness to the body and the sense of self. Frank argues that different people gravitate to different kinds of stories but whatever the choice of narrative; people have a “responsibility for their stories and for their bodies” (Frank, 52). Frank goes on to say that mere “survival does not include any particular responsibility other than surviving”

(Frank, 137). Rather than survivors, the sick, he argues, may become witnesses "responsible for telling what has happened and offering testimony to a truth that is generally unrecognized or suppressed" (Frank, 137). The truth he alludes to is, I believe, what is knowable through illness as a transformative spiritual experience, by which I mean the discovery of a story that makes sense of one's life even in the face of death. The element of testimony, as Frank describes it, is not unidirectional, but something that occurs in a "relationship of communicative bodies" (Frank, 143). In witnessing, the sick person as wounded storyteller takes responsibility for telling what may be uncomfortable or painful, and the listener responsibility for hearing the "truth" that may be equally so. Through rewriting themselves in story, the sick are transformed into wounded storytellers and, in relationship, testimony transforms the wounded storyteller into the wounded healer.

Together, the narrative and relational aspects of Charon and Frank's work act as tools for understanding illness in the context of the life stories in which they occur. Both offer a crucial aspect to understanding the illness experience through the narrative framework their work provides. The insightful approaches to illness taken by Arthur Frank and Rita Charon provide a basis for examining chronic illness and physical brokenness through narrative, challenging as well

as augmenting the predominately clinical and theoretical approaches to experiences of illness.

## Illness as Relational Experience

As Charon and Frank point out, the illness experience is also a relational experience. An essential component of what it means to be human is expressed in our ability to be in relationship. In the same way that the sick are not diseases separated from their person, we are not persons completely isolated from others. And so, the experience of chronic or protracted illness as much as it may make us strangers to ourselves and to others, must be considered in the context of the relationships in which we exist. As we compose the narratives of our lives, we do so for ourselves and for our listeners in order to make sense of the interruptions that are part of the natural course of life. Illness often presents a more acute form of this problem and exacerbates the need for a “meaningful story” to make sense of the disruption it causes. Certainly, our listeners include the practitioners to whom we tell our stories to seek physical healing or comfort, but our listeners are also those with whom we are in intimate relationship. Relationships with significant others require something of us. In Frank’s model, we are responsible to one another in the context of telling and listening to stories, and for that matter, in the context of

memory, but what I would like to suggest here is that responsibility to intimate others involves a degree of surrender of self to the other. The purely autonomous self that may enjoy full expression of personal agency does not exercise a full expression of his or her humanity. Relationships have the power to shift our focus from self-centered autonomous expressions of singular self pursuit (or what one wants) to the self in relationship centered approach that considers the others with whom we are in relationship. The chronically ill person may grasp for any expression of self determination in response to the diminished sense of self that results from illness, but this produces, I believe, a limited and even false sense of what it means to be human.

To explore this further, it is helpful to look at what it means to be in relationship with others. Two classic paradigms for understanding relationship that have deeply influenced Western civilization are found in Aristotle's model of friendship and the Judaic model of covenant that has its historical origins in the biblical account of the Israelites receiving the ten commandment at Mt. Sinai. It is there that God compels the Israelites to enter into a relationship of mutual obligation. God will guide and protect them and they in response will keep the law set forth in the commandments given to Moses. The covenant as it is expressed here is more than a mere contract between two parties. It is a trilateral relationship with God as

the unseen third party transforming our relationships from the mundane to the spiritual. As Jonathan Sacks describes, covenant is more a relationship in which “we open our ‘I’ to another’s ‘Thou’ [with] God *in between* [as] that [which] joins self to self through an act of covenantal kindness. That is *hesed* (kindness), the physical deed in which soul touches soul and the universe acquires a personal face” (54-55).

For Aristotle, friendship functions as the primary model of relationship. In Books VIII and IX of *Nicomachean Ethics*, he explores why we need friendships and how those friendships work. While often accused of narcissistic tendencies, Aristotle’s understanding of friendship does imply something helpful for understanding our responsibility to one another. For Aristotle, humans are social creatures and friendship a virtuous endeavor, “most indispensable for life” (Aristotle, 214). Friends, he says, “enhance our ability to think and to act” (Aristotle, 215). This is because for Aristotle, friends or intimate others act as another self, or another myself in whom I can see my actual self more critically and therefore more clearly (Aristotle, 266). As a mirror in which to better see and understand ourselves, friends are crucial to the process of self-knowledge. We more easily see in others what is difficult to ascertain in ourselves in isolation (Aristotle, 264). Personal autonomy is not a

good or outcome with which Aristotle is concerned, for only in friendship can we achieve the greatest degree of moral growth. As he says, "friendship is an association or community...[and as friends we] become better as [we] are active together and correct one another" (Aristotle, 271-272). These aspects of Aristotelian friendship, in which relationship with intimate others, to whom we are indelibly tied, are crucial to our understanding of ourselves. Within these relationships we find the place in which we are made better through our associations and experience the best kind of personal growth.

While Aristotle's notion of friendship is helpful for examining the relational aspect of illness, the addition of the concept of covenantal relationship may better facilitate an understanding of the importance responsibility plays in relationship, and even more so in relationships with the sick. Indeed, Jonathan Sacks suggests this very notion when he says that, "we discover God's image in ourself by discerning it in an other" (54). As Victor Frankl declares, "being human means being conscious and being responsible" (24). Embracing Frankl's notion, Jonathan Sacks equates the exercise of responsibility to others with a full expression of humanity and its absence with loss. He cites the failures of Biblical characters such as "Adam who loses paradise [and] Noah who declines into drunkenness" as narrative examples of the loss experienced as a result of abdicating responsibility and the story of



Babel as an example of what happens when we are responsible to no one but ourselves (Sacks, 146). In an extreme act of hubris, the biblical story tells us, the people of Babel “aspire[d] to reach heaven by technological prowess rather than moral conduct” and in so doing attempted to “take the place of God” (Sacks, 143-144). What the people of Babel, and often we, fail to understand according to Sacks is that “the word responsibility comes from the word response [and] implies the existence of an other who has legitimate claims on my conduct, for, or to, whom I am accountable” (Sacks, 144). This for Sacks is the very underpinning of covenantal relationship.

Responsibility, says Sacks, “is intrinsically relational” (144). The story of the sick person accountable to no one other than him or herself also represents a failure of responsibility. “The ethical is never private; in biblical terms, it is a matter of covenant between two parties, [in the story of Babel between] God and humanity” and in the story of the sick person, between the sick and their intimate others (Sacks, 144).

These two relational models work powerfully together as a means for understanding illness as spiritual transformation and providing the most helpful articulation of covenantal relationship through which to explore the nature of intimate relationships and more specifically the concept of responsibility between intimate others with whom we are in relationship. For Sacks, “...human life without

responsibility fails to do justice to human dignity..." (8). Applying his covenantal model of relationship, the impact obligation and responsibility to intimate others has on the experience of illness can act as a catalyst to inspire willingness in the sick person to undergo and even embrace the process of re-memberment despite the uncertainty that is the earmark of chronic illness.

## Illness as Shamanic Experience

While the idea of illness as a spiritually transformative experience is not novel, little focus has been given to illness as a specifically shamanic experience. The significance of the shamanic experience of dismemberment and re-memberment applied to chronic illness is that it functions as a spiritual framework for the very real experience of physical dismemberment and acts as a potential guide to spiritual re-memberment even when the body may remain broken.

The shamanic initiation experience, as described by Mircea Eliade, is a narrative for the "wounded storyteller" that unlike the restitution narrative described by Frank, does not require restoration of the patient to a previous and no longer available state. According to Eliade, the shaman's initiation experience of spiritual transformation is brought on by a crisis, often an illness or accident and is followed by a near death type of "out of body" experience that includes an experience of dismemberment. Broken in spiritual body, the shaman experiences reintegration in a new self. His or her bones are collected, fleshed with sinew and muscle and so he or she is "re-membered" and transformed. The following account by Eliade describes the stages of initiation as follows:

The important moments of a shamanic initiation are these five; first, torture and violent dismemberment of the body; second, scraping away of the flesh until the body is reduced to a skeleton; third, substitution of viscera and reveal of the blood; fourth, a period spent in Hell, during which the future shaman is taught by the souls of dead shamans and by 'demons'; fifth, an ascent to Heaven to obtain consecration from the God of Heaven (1994, 4).

The shaman's story is neither pleasant nor triumphant in the sense that he does not rise unscathed by his experience. Instead, he is like the biblical Jacob having wrestled with and been wounded by the stranger, only to discover he was wrestling with God, who changes his name to "Israel", meaning he who wrestles with God and prevails (Genesis 32: 24-32). Both figures carry with them and are defined spiritually by their wounds. Theirs is not a story one takes up willingly, but it is a narrative for the wounded body that does not demand physical restoration but offers instead spiritual transformation.

Recalling an exacerbation caused by a lesion on my brainstem, the shaman's account elicits from me a sense of kinship with him and I hear in an account of my own dismemberment an echo of his own.

At some point in the night, I have descended into the underworld. I know because I have woken in Hell. When I open my eyes the room spins violently counter-clockwise. Placing my feet on the floor, I stand shaking my head in futile effort to clear the double images. I list and capsize, falling to the floor retching and unable to lift myself out of the pool of my own vomit.

For months this spinning continues. The lesion has wreaked havoc on my equilibrium. My body does not know at any time where it is in space and I cannot navigate myself. I have lost all direction. I am unable to walk without falling, and to slow an image on which I wish to focus I must tilt into the spin, squinting to narrow the double image. Daily I try this with my daughter's face hoping to settle on a single image of her to make eye contact with her so that she will know that she is seen by me. When finally the whirlwind of images begins to slow and even after they have come to a halt, I find that I still do not know which way I am going. I have lost my center.

This is my dismemberment; disease has broken me. My physical self has been wounded but my loss of center is my loss of self, the self I know, and with whom I had become comfortable, the one whose stories I know and told with ease. My sense of loss is for this old

familiar self. Who am I when she is gone? I am not the self I was, admittedly, I did not even appreciate that girl until she was gone.

Illness for the shaman is an experience in which meaning and purpose can be found. From his experience he gains spiritual insight and the capacity to act as guide and healer to others. To borrow Frank's language, he becomes the wounded healer. Similar to the shaman's spiritual encounter, through illness, the sick are dismembered physically, emotionally, and spiritually. And like the shaman, the experience of dismemberment may be followed by re-memberment from which they may emerge transformed. The shaman in Eliade's account is transformed by his encounter with death, giving him the capacity and knowledge to communicate between the realms of life and death and the ability to heal others. Having already made the journey into death, he is uniquely equipped to act as guide to those who do not yet know their way. After similar encounter with death, the sick person I believe has the capacity, like the shaman, to be transformed by the experience and given new insight and the ability to share the fruits of this transfiguration with others.

Returning to my own experience, I find that my encounter with death was not only physical, but also spiritual. The sense of self that was lost was my spiritual self and in order for me to be transformed rather than annihilated by that loss, I had to allow my former self to

die. Like the Buddhist Zen master Hakuin's parable teaches, I had to release my hold over the abyss.

A man went astray and arrived at a spot which had never been trodden by the foot of man. Before him there yawned a bottomless chasm. His feet stood on the slippery moss of a rock and no secure foothold appeared around him. He could step neither forward nor backward. Only death awaited him. The vine which he grasped with his left hand and the tendril which he held with his right hand could offer him little help. His life hung as by a single thread. Were he to release both hands at once, his dry bones would come to naught. Thus it is with the Zen disciple. By pursuing a single *koan* [spiritual puzzle which has no "rational" answer upon which one meditates seeking spiritual insight] he comes to a point where he is as if dead and his will as if extinguished. This state is like a wide void over a deep chasm and no hold remains for hand or foot. All thoughts vanish and in his bosom burns hot anxiety. But then suddenly it occurs that with the *koan* both body and mind break. This is the instant when the hands are released over the abyss. In this sudden upsurge it is as if one drinks water and knows for oneself heat and cold. Great joy wells up. This is called rebirth (Heinrich, 258-259).

My despair is authored by my inability to locate my self, to find meaning in my experience and to find the story that will make sense of my experience. As Darrell Fasching writes, "the paradox is that one must will to plunge into that abyss, one must abandon oneself to despair and will one's own death. The way to the great joy...is through the great death..." (1988, 95). Giving in to that despair is the very act that releases me from it.

The shamanic narrative shifts the emphasis from a physical experience to a spiritual experience, from physical death to spiritual death. Through the process of spiritual dismemberment and re-memberment the shaman's story offers for the sick what the clinical cannot, the possibility of spiritual transformation (i.e., the discovery of meaning), even in the absence of physical renewal. Just as language and story suggest that we are more than a physical body, chronic illness is more than a physical experience.



## Conclusion

I said to my soul, be still, and let the dark come upon you... T.S. Eliot

As I have indicated, my thesis argument is that in order to fully understand the nature of the illness experience, we must explore the spiritual dimension, for it is here that out of brokenness and despair we may experience rebirth. The spiritual component of the shaman's initiation experience provides clues for understanding illness as spiritually transformative even in the absence of physical healing, and is strengthened when coupled with a sense of obligation to intimate others.

The experience of chronic illness is the experience of darkness. Illness is a form of St. John of the Cross' *Dark Night of the Soul* and for those experiencing protracted illness, it is a series of many dark nights. How to manage the darkness is to find meaning in the experience of it, to find that which is meaningful enough to allow us to trust the journey wherever it leads. Each of the previous models for managing illness have provided some practical and even vital component for understanding illness and finding meaning in the experience.

Clinical approaches to illness accomplish many things, in not only the curative, but also the palliative sense. What they cannot do is address the spiritual and emotional sides of illness. They do not have an answer for the contingent nature of the disease process, for the kind of suffering produced by uncertainty. Mark Hanson in *Pain Seeking Understanding* points out that “to be human is to claim the contingencies of life, including and especially suffering, and to find meaning in the encounter with them” (181). He goes on to say that “our very capacities to enter into a caring relationship with those who suffer are central to our moral lives and human identity” (181). I think what Hanson articulates here is one of the critical reasons for rejecting any purely clinical model for addressing chronic illness. Medicine gives us clinical answers, but not necessarily fully human answers. For that we must look beyond the physical. We must seek out meaning in illness that will allow us to embrace contingency and suffering thereby exercising more fully our capacity as humans.

Therefore what I am suggesting is that the kind of answer we need is not one only concerned with the physical aspect of illness, but with how we become more fully human or retain our humanity in the presence of chronic illness and all that it entails.

Narrative medicine gives us room to understand illness in the context of individual life stories and a way for clinicians to embrace

more than the physical suffering of their patients. Arthur Frank's work offers not only patients, but patient's bodies a voice through narrative, "injury becom[ing] the source of the potency of their stories" (xii).

With Frank, the sick can become wounded storytellers and wounded healers, but it is with the Shaman's initiation experience that we see a story the wounded can tell that articulates the way physical suffering can give birth to spiritual awakening or rebirth. The shaman is the bridge between the realm of the living and the realm of the dead that for the shaman is where sacred ancestors reside. What the shaman knows is that the living and the dead form one community and therefore, to quote Mitch Albom, author of *Tuesday's with Morrie*, "death may end a life, but it does not end a relationship." It is this relationship that will compel the sick to embrace the shaman's initiation and transformation through dismemberment and re-memberment as their own. This is the aspect I believe is missing from all of the other models and the aspect most crucial for compelling the sick to persevere through the dark night of chronic illness, through the myriad contingencies and unsettling state of uncertainty. The only component sufficient to encourage this kind of commitment in the face of death is through the claim intimate others have on each other within the covenantal relationship in which we are responsible to someone beyond ourselves.

For this reason, when I close my eyes to shut out pain or fear, the face and small voice of my daughter appear. This is what she calls me to do. As John Dunne suggests in *The Way of All the Earth*, consciousness projects an imagined path for our life, like a beacon guiding us through the darkness, but what gives us a sense of adventure is discovering the unexpected that lies ahead in the darkness. It is the unexpected that overturns and transforms our understanding of who we are and what our life means and causes us to re-narrate our life story. For we are always strangers to ourselves, who are more and other than we imagine ourselves to be.

Suffering, disappointment and death enrich us in unexpected ways. So Dunne suggests we must “consent to both gifts, the light and the darkness...to share the light is to share insight...to share the darkness is to share the sense of [spiritual] adventure which goes with the darkness and the journey into the night” (210, 216-217). This journey is the journey we all must make, the one that leads inevitably to death but when embraced rather than struggled against leads to insight that is the spiritual transformation that transcends even death (Dunne, 208).

The following narrative account shares a moment in the dying of a young patient of mine many years ago. When I reflected on this encounter, I was able to see how a narrative with which she was

familiar ("going to grandma's house") helped her find meaning in what she was experiencing in her dying. Along with that, I found traces of the shaman's experience in her final communications with her mother.

Before today, the last time I saw Emily was several weeks ago at her school. She was tired. Cancer does that to a body...dying does that. Still wanting to be with friends and teachers and to maintain some semblance of normalcy, her mother had reluctantly agreed to let her spend days or parts of days she felt up to it at school with her kindergarten class. Her teachers had placed a mat, the blue plastic folding kind, on the floor in the napping room. When I came to see her that day that is where I found her, laying on her side, her head haloed by downy blonde fuzz and resting on a tiny pillow that somehow managed to look large against her even smaller head. Her eyes were closed and her respirations coming in slight shallow breaths. I pulled another mat from nearby and lay down beside her. Face to face, when she opened her eyes, we smiled at one another and I knew her time would be soon.

Today she seems even smaller. I don't know how that can be, but her tiny frame is swallowed in her mother's embrace. I think to myself that perhaps it should be. I know when I see them there in each other's arms nestled in a chair that she is

nearly ready to die. This ordinary scene of maternal comfort is shrouded in their shared lingering and longing and I wait.

Speaking for the first time since I have arrived, she asks her mother, "Mommy, will you help me pack my bag?...I need to pack my bag." Fat tears spill from her mother's eyes and fall on Emily's yellow flowered pajama's. Unsure what it means, her mother looks over at me and I smile a little, silently nodding my head urging her to follow along. She carries Emily into her room to pack her pink suitcase with the words "going to grandma's" in big bubble letters. Her mother puts her favorite books and pajamas in and tucks the blanket Emily holds out on top.

Scooping her up she carries her back to the overstuffed chair, dragging the case behind her. Settled once again, her mother stroking the fine wisps of her hair she says, "Ok Mommy...I'm ready to go now." Fresh tears welling in her eyes, "Go?..Go where sweetheart?" her mother replies. "On my trip...keep this for me, Mommy" she says taking her stuffed bunny from her own chest and pressing it to her mothers. Closing her eyes, still holding her bunny to her mother's heart, Emily took her final breath.

Emily has stayed with me. I often think of her and her encounter with death. She understood her dying as a journey, a trip

she would make like the ones she had made to her grandmother's house. So she packed her bag, taking the things she might need along with her, but also leaving something behind. Packing her suitcase was a symbol of preparing for her death. Leaving the bunny, I think, was the symbol of the connection with her mother that would remain unbroken by her death. Emily's story, like the one's told by Lorraine Hedtke and John Winslade in *Re-Membering Lives: Conversations with the dying and the Bereaved*, is not about "producing closure or completing unfinished business [but rather] about relationship going on and [...] what might continue rather than what might be lost" (5). The last conversation with her mother was anything but final. Instead, it was an invitation to continue the conversation even in death. As Hedtke and Winslade suggest, "remembering conversations can start long before death [in order to] construct a deliberate future that continues to include [a loved one]" (5-6). Beginning those conversations in the way they describe makes a place for the dying person's "voice to carry on, [...] to incorporate [their] voice [...] and be responsible for carrying on its speaking" (7). Furthermore, the ongoing connection acts as a comfort to those with whom the dying are in relationship.

I too consider the possibility of constructing this conversation with my daughter as a way to prepare us both for the next crisis, for

even the final one. She lays claim on my life, as do the others whom I love and who love me in return. She whispers it there in the dark of death's night and I am compelled to respond. Through my obligation to her, to those I love, I find meaning in what appears meaningless. My story becomes one of rebirth where what is born is not something separate from myself, but rather a new self, fledgling and tentative, subject still to the contingencies of my disease, to uncertainty...fully aware that to let go of my hold over the abyss is to embrace that darkness, to give myself over to it. My efforts to exercise radical autonomy in the shadow of death are pursuits for control over an uncertain outcome, one beyond my control. They are limited to the physical journey and not representative of the spiritual journey I am making in which I do not seek to control the journey, to shut out the darkness, but to trust it. Entering the shaman's story, my death does not come as the end, the separation I fear. Through my relationships the spiritual realms of life and death are bridged and my physical death, whenever it comes, need not, like the darkness, be feared or rejected, for death may end my life but not my relationships.



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