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# Terminal and Life-Threatening Conditions: Finding Meaning Through Mortality

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TERMINAL AND LIFE-THREATENING CONDITIONS: FINDING MEANING  
THROUGH MORTALITY

A thesis submitted to  
Regis College  
The Honors Program  
in partial fulfillment of the requirements  
for Graduation with Honors

by

Ericson Stoen

May 2013



To the memory of

**Maegan Janel Isaak**

*“You were a thunderstorm, and yet, you were a beam of light that shown through the clouds”*

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## Introduction

“*You have lymphoma*. These words changed my life...” (Hosinski, 2000). Like Father Tom Hosinski, the lives of the many people each day worldwide who are told of their imminent death are forever altered by their diagnosis, regardless of the disease that is delivering what is, in essence, a death sentence. Within the few seconds required to utter the condemning words, an individual’s sense of identity, worth, and personal meaning are called into question, concepts with which few are inherently equipped to grapple.

Abraham Maslow attempted to help humanity answer some aspects of these monumental questions in his introduction of one of the most foundational theories in psychology in 1943 in an essay entitled “A Theory of Human Motivation:” the hierarchy of needs. He later extrapolated upon these ideas in his book *Motivation and Personality*, which was published in 1954. This book highlights the importance of the idea of the hierarchy of needs, insisting that some human needs are of a greater priority than others. At the bottom of this hierarchy are the basic, or physiological, needs (Maslow, 1954). Depending on how one defines the word “needs,” to some extent, one may argue that the higher-order “needs” are actually desires, since they don’t directly affect one’s ability to function on a physiological level. However, many psychologists and philosophers would adamantly disagree with this assertion; the top of the hierarchy includes such themes as morality and problem solving (grouped under self-actualization). In fact, some even interpret this term to imply some level of a sense of meaning. As Socrates once said, “the

unexamined life is not worth living,” a statement that especially supports the top of Maslow’s Hierarchy (see Figure 1).

The physiological needs, which reside at the bottom of the hierarchy, consist of basic homeostatic functions such as the maintenance of the oxygen content of the blood, mineral concentration, and food, water, and shelter availability. In order for the individual to move to satisfy the higher-order needs, he must first satisfy the most basic ones; otherwise, he will be consumed by the desire to fulfill these needs to the point of

interference. Thus, at their most basic level, all humans have the motivation to remain alive and, barring any radical changes in brain chemistry, this can be expected from all higher organisms. All higher needs are prioritized based on extreme deficiencies in



Figure 1: A graphic depiction of Maslow’s Hierarchy of Needs; taken from Zalenski & Raspa (2006).

the physiological needs and, as a result, will often be trivialized by these more urgent, lower-level motivations. Examples may be found in which individuals work toward self-actualization without first addressing lower needs, but these tend to occur only in drastic

and salient circumstances (as for those who undertake hunger strikes), and are far from the norm.

Next, are the needs surrounding safety, being defined as those needs such as “security; stability; dependency; protection; freedom from fear, from anxiety and chaos...order, law...” (Maslow, 1954, 39). From here, Maslow describes the “belongingness and love needs,” the “esteem needs,” and finally, the “need for self-actualization,” (meaning the realization of an individual’s full potential) (Maslow, 1954). As with the physiological needs, one may not be equipped to work to achieve the goals of the next tier of motivation until one feels that his needs have been met on the previous tier completely.

This theory regarding basic human motivation is especially interesting when applied to scenarios in which individuals are coping with terminal or life-threatening illnesses that are by definition, “leading ultimately to death,” (Merriam-Webster, 2013). For the purpose of this work, “life-threatening” and “terminal” will take on a similar meaning, since in both cases individuals are often driven to reevaluate the ways in which they have prioritized and chosen to live their lives. In my opinion, individuals living in societies in which modern medicine is utilized who are afflicted by these type of illnesses are perhaps more likely to have complex motivations—motivations that not only dictate their choices, but also a strong sense of purpose that empowers them to continue life and their higher sense of purpose in spite of their illnesses.

This sentiment is echoed (though admittedly complicated) by Viktor Frankl in his memoir *Man’s Search for Meaning*, in which he introduces a psychological theory called

logotherapy, which asserts that man's primary driving force is his need to find personal meaning (Frankl, 2006). This is different from Maslow's theory by its implicit assertion that needs other than meaning do not need to be satisfied prior to the contemplation of meaning. Interestingly, Frankl exemplified this via his time imprisoned in various concentration camps during World War II. He was constantly ruminating over his sense of personal meaning, though one can be all but certain that his physiological, safety, love and belonging, and esteem needs were *not* being met at the time.

While he recognizes that our time on Earth is limited, Frankl insists that this is not a barrier to establishing personal meaning, nor does it devalue the process or concept in any substantial way. Rather, he insists, "At any moment, man must decide, for better or for worse, what will be the monument of his existence," (Frankl, 2006, 121) suggesting that all of our choices are ultimately driven by our individual sense of purpose.

Interestingly, a survey was conducted in the early 2000s that found that 89% of people believe that man "needs 'something' for the sake of which to live;" Frankl integrated the results of his study into his theory of logotherapy (as cited by Frankl, 2006, 99).

Throughout the remainder of this thesis, this theory will be referred to as a system or paradigm of meaning-making. Together, I believe Frankl and Maslow provide an effective model for navigating the human condition, especially when one is suffering from a life-threatening illness.

The idea that every ill individual is different is an obvious and pervasive one; however for the sake of simplicity, throughout this thesis I will be asserting that many individuals coping with terminal or life-threatening illnesses find their (possibly

modified) personal meaning through four distinct and relatively broad sources: fear, disregard, service, and spirituality, each of which will be extrapolated upon. By the end of this work, I would like to convince the reader that there is one meaning-making system that is more effective than the others (i.e. empowers individuals to maintain a more positive attitude toward their illnesses, better prepares individuals for the reality that is their upcoming death, etc.), or at the very least, invite the reader to be better able to understand the distinct positive and negative attributes of each paradigm.

Additionally, since the purpose that we attribute to our lives is what drives many of the choices that we make, the question arises of whether or not there is a “right” way to fulfill this purpose. Is there a correct way to navigate life with a terminal or life-threatening illness? As someone who was strongly influenced by a Jesuit education, I have found that this question can be rephrased, “how ought we to live?” As I enter medical school and life beyond the immediate Regis community, I have found that this question is one that will continue to plague the world that surrounds me. Ultimately, the goal of this investigation is to determine what that “ought” looks like for individuals who are afflicted with terminal or life-threatening illness.

Throughout this work (and for each of the paradigms), a brief introduction will be supplied, which generally describes the context for each of the meaning making systems that are being utilized. Next, a case study will be provided that will allow the reader to see the real-world connection of each of these meaning making systems, along with some blatant benefits and detriments that are found in each system. Following this, a basic analysis of each system will show the cross-disciplinary complexities of each meaning

making system, which will hopefully provide a more objective view of each of the distinct systems. Finally, I will provide a brief conclusion that will help to determine if there is (or should be) an “ought” to navigating life with a terminal or life-threatening illness.

## Fear in Terminal and Life-Threatening Illness

### FEAR

Within the context of survival, fear is an evolutionarily favored attribute that encourages organisms to distance themselves from threats that will put them in danger. For individuals that have been diagnosed with a terminal or life-threatening illness, fear can be a positive attribute, dissuading the individual from engaging in activities or behaviors that might negatively affect his health. However, it can also be a negative attribute, one that inhibits many facets of one's life, acting as a barrier in achieving many of the goals or aspirations that he has held. In either case, fear has the capacity to strongly influence the ways in which one chooses to live his life with a terminal or life-threatening illness, and may ultimately even become his primary form of meaning-making.

### CASE STUDY

As one might imagine, it can be relatively easy to become overwhelmed as a result of the diagnosis of a terminal or life-threatening illness. In Richard M. Cohen's personal recollection *Strong at the Broken Places: Voices of Illness, A Chorus of Hope* (2008), he reflects on this feeling by telling his story, both of his own struggle with multiple sclerosis, as well as his encounters with five individuals, each with a different journey and distinct terminal illness, complete with different takes on their limitations. In an especially poignant series of encounters with a woman named Denise, Richard saw how an individual can become crippled by fear and despair as a result of his or her illness,

something that he is concerned may influence his own life as his condition worsens with age.

At the time that Richard met Denise, she had fairly advanced Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease and motor neurone disease. ALS is a condition in which the motor neurons that control voluntary movement in the skeletal muscles slowly die. The first symptoms displayed are often difficulty swallowing or shortness of breath. Early on, Denise expressed extreme frustration at the fact that she could no longer cry, as the buildup of mucus may have obstructed her airway, causing her to choke. As the disease progresses, multiple muscle groups may be affected, often debilitating individuals to the point that they need constant supervision (for eating, urinating, etc.) and the use of an artificial respirator. Most patients die within 3-5 years of diagnosis from respiratory failure (Jasmin, 2012). Currently, the precise cause of ALS is largely unknown, though several independent events seem to lead to a manifestation of the disorder. For example, there is a genetic explanation that can be implicated in roughly 1 in 10 cases. In many of these genetic cases, a mutation in the gene encoding the enzyme superoxide dismutase is present, leading to an ineffective degradation of the toxic, free radical superoxide ion, which negatively affects motor neurons by contributing to their degeneration (Bedlack, 2011).

The author of *Strong at the Broken Places* conveys the seriousness of the disorder by describing ALS as being:

As bad as it gets, bringing on terror, not simply fear. The disease usually strikes people between the ages of 40 and 70. As many as thirty-thousand Americans,



more men than women, are afflicted at any given time. Every ninety minutes, someone is diagnosed with or dies from ALS. (Cohen, 2008, 17)

Because of the grim prognosis of the disease, Denise, like most, did not take the news of her illness well, especially after hearing from her doctor that the diagnosis of ALS is like a death sentence, and that there was nothing more that the medical field could provide her, aside from a somewhat comfortable death (Cohen, 2008, 22). Denise then fell into a deep depression (one that would be expected to some degree in anyone with a similar diagnosis), quit her job, and was overwhelmed by a feeling of hopelessness.

As her disease worsened and her symptoms became more and more obvious even to perfect strangers, Denise struggled to retain her authentic core; what previously made her herself was being challenged, and it was essential for some modification to occur of both her understanding of herself as well as of her purpose. In the preface of the book, the author suggests that, following a diagnosis, “Our views of ourselves as normal human beings making our way in a neutral world is challenged as, in the eyes of others, we become our illnesses,” (Cohen, 2008, xvi). From then on, the disease was part of her identity, whether she liked it or not; this can be seen through the way that she integrated conversations about her illness into everyday conversation (since certain behaviors *must* be addressed, such as slurring one’s words constantly), and also through her mannerisms. For example, as the disease continued to deteriorate her nervous system, she had an increasingly difficult time speaking and forming even the most basic of sentences, something that largely defined the words that she chose to articulate, the tone that she

vouched to adopt, and the length of conversations that she was willing to participate in, since conversing required much more focus and energy.

In addition, as her ALS progressed, Denise was forced to reassess much of her life, including her goals. Many of the goals that she wanted to achieve at some point during her life would not be possible, and even the things that she could do would have to be adjusted in many ways to accommodate the newfound burden that was her illness. However, she also saw that her disease had the potential to enrich the time that she had left with a much greater understanding of others and their struggles that is largely inaccessible to the majority of people who are unaffected by any sort of life-threatening, or even chronic, condition. She conveyed this, stating:

“It is all gone,” she said...describ[ing] how ALS had robbed her of her dreams and transformed her life. And she spoke of an empathy that had been born. “I see life differently now. When I see someone in a wheelchair or on a walker, I want to go up and hug them and say, ‘I am sorry you are sick. I know how you feel,’”

(Cohen, 2008, 12)

For quite a while after her diagnosis, Denise let the disease take her life from her: it turned menial tasks into marathons, and caused her to stop formulating aspirations at all. In fact, one could even say that she was paralyzed partially by her disease, but also appreciably by her fear of making her condition worse, and losing even some of the precious time that she had left. Through Denise’s story, one can see the powerful impact that the diagnosis of a terminal or life-threatening illness may have on a person’s outlook; this can be very dangerous, and may even drastically change the way that that

individual views the world as a whole. At her lowest point, Denise could easily be described as a cynic.

## ANALYSIS

In the world of terminal and life-threatening illnesses, a story like Denise's is not at all uncommon. Fear, by its very nature, is inhibitory to many facets of a functioning organism. Physiologically, when higher organisms are faced with a stressor, the sympathetic component of the autonomic nervous system is activated by the hypothalamus, which is notified of the threat by the amygdala (located in the brain), imparting a greater degree of action where it matters (e.g. stimulation of the muscles, eyes, and lungs) and decreasing activity where it isn't of immediate concern (e.g. inhibition of digestion, urination, and thoughts regarding matters unrelated to the current stressor). The hypothalamus sends signals to the adrenal glands, causing them to release epinephrine, which is effectively the catalyst for the "fight-or-flight" response as a whole (Harvard Health Publications, 2011).

While immediate stressors, such as a lion entering one's house, would tend to result in a larger manifestation of this effect, recurrent stressors, such as the persistence of a chronic illness, tend to elicit a similar, less intense effect, though one that is more drawn out, often over a long period of time. Numerous studies have shown that high levels of stress have negative effects, both psychologically and physiologically; in fact, there is substantial evidence that prolonged stress may even lead to heart disease, depression, and addiction (Harvard Health Publications, 2011). Even those of us who do not live our lives with the knowledge that we have a terminal illness can become easily

aware of a sense of anxiety when we think about the notion of death. For those with a terminal illness, that feeling is amplified, with a much stronger sense of urgency than the one that we may feel normally (and one with a much more dramatic physiological and psychological response to the stressor that may influence future behavior).

Because of this fear of the unknown, many individuals with life-threatening conditions approach their lives with newfound perspectives. Many go through a phase at some point (though some never emerge) in which they do not think that it is worth their time, energy, or the possibility of exacerbating their condition to attempt to attain their aspirations or goals. In fact, one study asserts that “organizational defenses” may exist, which alter the world around the individuals afflicted by terminal illness in order to limit the anxiety produced by knowledge of their terminal or life-threatening illness. These defenses include denial, splitting (lack of ability to integrate negative and positive aspects into a situation or person), idealization, and projective identification (the action of imparting one’s ego onto another with the expectation that this person will follow and personify the intended projection) (Hayslip, 1997). When these defense mechanisms are not optimally effective, the individual may experience anxiety to an unhealthy degree. This may even result in, as previously stated, an inhibition of working toward one’s goals and aspirations.

Interestingly, when introduced to the prospect of terminal illness, individuals tend to use the defense mechanisms of rationalization, repression, and denial roughly equally (Hayslip, 1997). While repression and denial may seem similar when viewed as defense mechanisms, repression serves to restrain feelings, while those in denial refuse to

acknowledge them. Those with extreme death anxiety are obviously more likely to use the latter two, since individuals who are lucid enough to recognize and attribute the source of their feelings to a specific aspect of their life are more able to deal with their fear, whereas those who restrain or do not acknowledge their feelings may not ever be able to successfully overcome their underlying anxiety or fear, and thus may live an appreciably inhibited life.

On the other hand, clinging too tightly to defense mechanisms as a means of alleviating anxiety may also be an unhealthy way of dealing with one's illness. Rather than coming to terms with an illness, someone may choose to be in denial regarding his disease, thus living his life irrespective of the potential consequences, and legitimately having the possibility of exacerbating his condition. While this may be somewhat liberating for the individual who decides to view his illness (or rather, ignore the illness) via this paradigm, it is extremely risky; in fact, it may even interestingly result in someone whose meaning is accomplished through the disregard of his illness *by* this fear, a sort of combination of two meaning-making systems.

In their study, Hayslip et al. (1997) found that individuals who were HIV positive tended to be more likely to have hopeless outlooks, and have lower life satisfaction rates than their healthy, matched controls. This study essentially suggests that simply by virtue of being diagnosed with a terminal illness, one is more likely to become inhibited, whether by fear or by some other means. It is also possible that there is a dynamic interplay between fear and hopelessness, each fueling the other, both of which may

prompt the individual suffering from the terminal or life-threatening illness to abandon hope, and ignore their goals and aspirations due to this psychological barrier.

However, the knowledge that one has developed a terminal illness is never easy knowledge to endure. Regardless of one's expectations for his life, some aspirations are not even capable of being achieved anymore, and others would require vast modification and expedition. Despite this, however, I believe that the idea that approaching one's life-threatening illness from the perspective of not pursuing goals due to a sense of paralyzing fear is not necessarily legitimate. Rather, I believe that this inhibitory fear serves as an obstacle that all individuals afflicted with a terminal illness must overcome at some point, and to some degree. Thus, while it is true that some aspirations must be abandoned due to physical or mental restrictions, a balance between restraint and recklessness must be maintained for all those who are suffering from these types of illness.

In a poignant example, Denise finally took the trip of a lifetime that she had dreamt of when she had finally partially overcome her fear of exacerbating her ALS. Eventually, after her disease had put her in a wheelchair, she decided to throw fear to the wind and go on the cruise to Antarctica she had planned for over the course of many years. She stated, "As my ALS progresses, my left hand and leg are becoming weaker. That has made me more determined than ever. I have to pursue my dreams," (Cohen, 2008, 31). In fact, her disorder may have even been the catalyst that she had always needed. Regarding this, Denise said:

If I did not have ALS, I would not be going there. There would have been no time or incentive to live the way you are supposed to...I would be too busy living a life I did not care about. I have changed. I'm doing things I would never have done.  
(Cohen, 2008, 32)

In my opinion, this determination is crucial; if one allows the disorder to *become* his life, he will be left with nothing but a fearful shell of what he once was. However, accomplishing essential goals is, by its very nature, liberating and certainly helps individuals to reclaim their autonomy. While the journey was completely fulfilling and yet extremely tiring, Denise emerged and has been willing to fight the disorder, despite its constant encroachment on her life. Though her ALS will almost certainly eventually take her life, Denise was able to regain a substantial amount of control of her life by taking this whirlwind trip.

To some degree, though, Denise was forced to accept the fact that her disease would affect her more and more each day, and that ultimately her prognosis was less-than-favorable, hence the haste with which she was forced to plan and execute her trip. Whether one is ready for it or not, the deterioration of his condition in a terminal condition is often a near certainty, so this acceptance is not really something that is important, anyway; the illness will progress whether the host wants it to or not. As far as accepting her illness as a part of her identity, however, Denise asserts:

Acceptance is not a real-world concept...To make peace with an illness becomes appeasement. I need frustration and anger to keep me going. The bitter flailing at

what I can no longer do with my body becomes an emotionally safer target than the illness itself. (Cohen, 2008, 43)

In Denise's opinion, an illness is only a part of you insofar as you make it a part of you. For her, it was important that her ALS was *not* one of her defining characteristics, even though to strangers, it was certainly one of her most apparent ones.

Ultimately, though a terminal or life-threatening illness will certainly affect every facet of the lives of the individuals who are afflicted with them, these individuals must retain what makes them who they are. If, in order to establish his identity or basis for his purpose, an individual must occasionally do something that deviates from the generally restricted agenda of an individual with terminal illness, he *must* do it, especially if it works to overcome the barrier that is fear. In my opinion, working past this barrier will allow for further personal growth, allowing one to more easily transition into the sick role and the phase of his life associated with dying. Additionally, the afflicted individual will be better equipped to offer support and reassurance to his family and friends when he has finally dealt with the inhibitory fear that is practically inherent in a diagnosis such as that received by Denise.



## Disregard in Terminal and Life-Threatening Illness

### DISREGARD

In this section, the term “disregard” is meant as a sort of middle ground between the other distinct terms of “denial” and “defiance.” Depending on the individual, the diagnosis of a terminal or life-threatening illness may cause a reaction in which the individual rejects the idea of his illness. This may mean that he acts in ways that do not take the complexities or complications of his illness into account; it may also mean that he decides that the illness is not in control, and he takes his own life; or it may mean that he simply refuses treatment. These different approaches to viewing illness may ultimately become the means by which the individual finds purpose in his life.

### CASE STUDY

In a case study provided by Leikin and McCormick (1991), a nineteen-year-old male named Henry is introduced, who had been diagnosed with non-Hodgkin’s lymphoma five months prior to the time that the case study was documented. This cancer type is a cancer affecting the lymphoid tissue, usually beginning with the B lymphocytes, the primary contributors to the humoral immune system equipped with the capacity to synthesize antibodies, which are proteins that detect foreign or abnormal signatures in the body (i.e. antigens) and target them for destruction (Dugdale III, 2012). Interestingly, this cancer often affects individuals with compromised immune systems and usually requires more aggressive treatment than chemotherapy alone. Additionally, non-Hodgkin’s lymphoma has a highly variable cure rate, as the progression of the disease is largely

contingent upon the initial area of transformation. For example, if the cancer originates in an area that is localized near an entrance to the lymphatic system, it is much more capable of metastasis than if it were localized elsewhere.

Though Henry knew that his prognosis was not favorable, he decided to pursue chemotherapy as a mode of treatment. During this time he went into a temporary remission; despite this, Henry reported feeling “too snowed out to do anything” as a result of the analgesic medication that he was taking at the time. Further, this remission did not last long. Following the largely unsuccessful chemotherapy regimen and the news that his cancer was certain to be terminal, Henry went to his oncology clinic and thanked everyone that had been there for him throughout his demanding treatment, and even gave away some of his favorite possessions to these individuals. At this point, he was in considerable pain with no positive outlook in sight, as all he had was the medication to dull the relentless pain. Upon his leaving the clinic, some of the staff members realized that Henry had sufficient prescribed narcotics in his home to effectively end his life. This, in combination with his recent visit, concerned the staff of the clinic, since during his previous relapse he had explicitly stated that he had intentions to end his life prematurely if his cancer were to return, because he did not want to deal with another relapse with such a grim prognosis. At that point, it appeared that Henry was able to rationalize to himself that the detriments to his life as a result of the illness would outweigh the benefits of continuing to fight.

## ANALYSIS

An important minority of individuals see terminal illness as a type of justification to live their lives in whatever way they wish. In Henry's case, this means violating the inherent human motivation of survival, though most would certainly find this understandable, as his prognosis was not at all favorable. However, for others this can mean intentionally not seeking medical attention or even exacerbating one's condition through other means (such as appreciable alcohol or drug use). Ultimately, Henry's story is not much different than these examples of disregard of one's condition since they all share the distinct commonality of a blatant disregard of a life (or the potentiality thereof) that the afflicted individual once knew, but is no longer willing to pursue. It is possible that, in the absence of a sufficient meaning-making system, an individual may stagnate here; alternatively, there is also a chance that this disregard serves as a comprehensive purpose-making paradigm, one that can take on a number of different and distinct manifestations.

While there is little doubt that most would find Henry's story extremely saddening since he was so young and chose to deal with the illness in such a resigned way, variations of it are far from exceptional. Although there are not many reports of individuals who quietly take their own lives because they want to escape their disease, there are, however, some more high-profile ones. The media often highlights these cases more aggressively than those that entail an average individual taking his life as a result of illness. In an interesting response to his disease, on March 11, 2012, Dr. Peter Goodwin chose to take his own life. He was surrounded by a diverse mixture of family and friends,

and left behind a medical legacy (and, for that matter, a political and ethical controversy) (Sabatier, 2012). At the age of 82, Goodwin received the news that he had corticobasal degeneration, a fatal neurodegenerative disease characterized by impaired movement and cognitive ability. His already established fame was related to his adamant insistence to Oregon lawmakers to legalize physician-assisted suicide, or rather, as they call it in Oregon, “death with dignity,” (Sabatier, 2012). To be in accordance with the requirements of this law, one must receive a six-month prognosis in order to be prescribed the life-terminating medications, and must be lucid enough to make healthcare decisions for himself. In the eyes of Dr. Goodwin, the utilization of this law is not as much of a choice as that of suicide, since death is impending and inevitable. For all of us, death is not a matter of “if” but of “when,” but this is especially so for those with life-threatening illness; those who chose to utilize the law do so because they are then able to die on their own terms and finalize their lives without the threat of being caught off guard by death.

The controversy behind this law lies in the interpretation that the quality of life to be gained during those six months would be inferior to the happiness that would be gained by expediting the entire process of dying. Throughout his later life, Goodwin was a major advocate of the law, stating that he first realized the need for the law when a patient with a terminal spinal tumor was in immense pain, but he had to deny him a life-ending prescription. Upon receiving his own 6 month prognosis, Goodwin chose to “die with dignity” before he could no longer be considered lucid enough to make the decision (Sabatier, 2012).

Though Dr. Goodwin's choice to end his life appears to be a completely conscious and rational one, not all such decisions truly are. Many individuals take their own lives impulsively, without an illness motivating the decision, often because of rash emotions, which can be influenced by various psychological pathologies. It is common knowledge that within the course of a few hours, most people experience a wealth of distinct (and often trivial) emotions of varying intensity that result from the dynamic stimuli that the individuals are exposed to. Of this emotion, there is a great diversity depending on the person and their previous experiences and genetic background. However, a wide array of psychological disorders can effectively skew this manifestation of emotion, producing more homogenized (and often, culturally inappropriate) emotional responses. As a result, it is possible that one's lucidity or rationality is sometimes affected, thus calling one's decision-making competency into question. One of the most prevalent disorders that has been found to have this effect is depression.

The World Health Organization (WHO) defines depression as "a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration." As previously stated, it is an extremely common disorder—depression affects roughly 121 million people worldwide (WHO, 2012). It is so common, in fact, that many people with depression do not know or understand the feelings that are characteristic of the disorder. Because of this, treatment is often not feasible for a large portion of the affected population. Additionally, the disorder can manifest itself in a number of unique ways and symptom combinations, and patients may interpret their condition differently. Further, it

can be very difficult for others who are close to a depressed individual to understand the reason for and background behind their depression; they often completely fail at “putting themselves in the other’s shoes,” and thus may not be able to see the warning signs of an individual who is depressed, as the disorder transcends simple sadness. This depression can exacerbate an ill person’s condition and outlook of his illness, thus creating hopelessness and sometimes apathy.

Since people of all types are at risk of becoming depressed, there is little doubt that depression is a multi-faceted disease. Surprisingly, the biological cause of the disease is still under investigation and interestingly, the conventional wisdom that a chemical imbalance rooted in the neurotransmitter serotonin is the culprit is not necessarily completely true (Spiegel, 2012). Rather, many scientists believe that the biological cause of the disorder has a combination of influences, including environmental, evolutionary, and social factors. According to the Mayo Clinic, depression may be caused by a combination of biological differences among people, neurotransmitters, hormones, inherited traits, life events, and early childhood trauma (Mayo Clinic, 2012). Because of the fact that many of those that are afflicted may not receive effective treatment due to the differences in manifestations and underlying causes, a major concern with the disease is that it has a very large statistical potential to be co-pathological with suicide. Additionally, due to the inherent shock of being diagnosed with a life-threatening illness, one may be at an increased risk of developing depression, a disorder capable of bringing into question an individual’s ability to make rational decisions regarding his health.

There is little question that suicide is a controversial issue in the United States, and for that matter, in the world. Encouragingly, however, in the United States only about 1.53% of all deaths are from suicides (WHO, 2002). On the other hand, since nearly one in five adults in America suffer from chronic depression, it is concerning that there are that many people whose minds are not necessarily guiding them in rational directions; this helps to partially elucidate the drastically increased rate of suicide in this afflicted group. Because depression and suicide are both highly stigmatized, society does not readily talk about either of them and depressed individuals are often seen as “crazy,” possibly exacerbating their depression and creating a vicious circle.

Despite the predominantly negative attitude regarding suicide, individuals with terminal illness were found to have a much higher suicide rate than that of the general population. One study found that one in ten suicidal individuals suffered from chronic or terminal illness (Bazalgette, 2011). In the United States, it was found that AIDS patients had suicide rates that were more than thirty-five times that of the general population (Kolata, 1988). While these statistics may seem relatively extreme, there is one piece of potentially explanatory evidence: of the 1 in 4 terminally ill individuals who expressed the desire to die, all had clinically diagnosable symptoms of depression (Brown, Henteleff, Barakat, and Rowe, 1986). While this is certainly logical, it brings into question the decision-making competency of Dr. Goodwin (and other people with terminal or life-threatening illnesses), since the odds are good that he was, in fact, depressed and, by extension, not thinking rationally. This evidence suggests that depression can be a predominantly conditional disorder, rather than a largely biological

one, due to the fact that the acquisition of the knowledge that death was relatively imminent caused an increase in the overall rate of disease. However, this is not to say that one can simply discount the fact that there are certainly lucid individuals who contemplate and execute their suicidal ideation. Additionally, while suicide may be an example of disregard, there are many other means by which to accomplish the overall disregard of one's terminal or life-threatening illness.

Overall, this disregard for one's terminal or life-threatening illness may actually be a positive reaction for the individual afflicted with it. Disregard of one's illness does not necessarily mean that the individual is depressed or suicidal; rather, it may mean that the individual is choosing to live his life without any barriers. Sometimes this may mean that he takes part in activities that negatively affect his health (e.g. drug addiction), but in other instances it may mean that he simply does not consistently adhere to his treatment plan.

In addition, since I believe that the ideas of rationality and lucidity are almost completely socially constructed ones, perhaps one may not be considered rational simply by virtue of being terminally ill. Because the vast majority of society is not directly struggling with its mortality at any given time, the constructs of rationality and lucidity are not made to take into account the difficulty and seriousness of navigating life with a life-threatening condition. Thus, perhaps it is important to qualify these terms with the circumstances that an individual is plagued with, such as the severity of his medical conditions.



Despite the predominantly negative social view of those who “act out” as a result of an illness, it is possible that this is simply part of the grieving process for people with terminal illness. Even though death from the illness is not a certainty, depending on the disease, there can be a very high probability of mortality. As a result, it is important that a sort of modified grieving process occurs. Afflicted people may struggle to reconcile the idea that they have very little time left to live, but so much that they wish to accomplish. Thus, they may choose to live their lives irrespective of their condition. However, the time frame within which this negotiation of life and death occurs can now be highly variable, since the knowledge of death can be far in the future, and each individual’s method of coping varies.

In her book *On Death and Dying*, Dr. Elisabeth Kubler-Ross introduced to the world the 5 stages of dying: denial, anger, bargaining, depression, and acceptance (1969). In those patients with terminal illness, however, it is possible that afflicted individuals often begin to show these stages immediately upon diagnosis. Additionally, since there may be a very long time before one’s condition worsens to the point of dying, it is possible to stagnate in a particular stage. Because of this, an elongated “denial” phase may be observed, explaining those who act in ways that exacerbate their condition. Additionally, this mindset may lend itself to the concept of “living life to the fullest,” “living like you’re dying,” or even taking unnecessary risks.

On the other hand, this disregard for one’s life and aspirations may serve as an effective meaning-making system in and of itself. Perhaps the individuals that deal with their illnesses in this way are the type of people who “live fast and die young” to begin

with and, because of their shortened time on earth, they feel they need to compensate and approach life more like a whirlwind. Also, for those who directly end their life, rather than disregarding treatment, it is possible that they feel that they have done all that is possible with the time that they have been given, and all remaining time would simply go to waste. Perhaps they do not feel that they can continue to live out their purpose any longer, because of the impediment that their disease presents. Ultimately, though, I believe that the disregard of one's illness is not a legitimate meaning-making system, since "living life to the fullest" is not always the same as living a life of purpose.

However, in the case of Henry, Marzuh et al. (1988) (through Leikin & McCormick [1991]) assert that this reevaluation step is a necessity, underscoring the need for lucidity in making decisions as drastic as taking one's own life. Although they do agree that, as autonomous beings, we have the right to end our lives, Leikin and McCormick do not see this as a legitimate meaning-making paradigm in all cases. Rather than letting him make the decision alone, they insist, "Encouraging an open discussion with Henry about his present physical condition, his emotional reaction to the illness, and the prospect of dying would certainly seem warranted," (Leikin & McCormick, 1991). However, they also raise the important question: where do these interventions end? Are we obligated to constantly check the emotional and psychological state of everyone afflicted with a terminal or life-threatening illness? When can Henry (or really, anyone with a terminal illness) prove that he is lucid enough to want to make the decision? Since they are violating one of our most fundamental motivations as organisms to perpetuate our genes and live, is anyone who has suicidal ideation truly lucid?

Overall, Leikin & McCormick feel that the validity of ending one's life (and by extension, the disregard of one's health) as a meaning-making system is largely contingent on the morality and contextual "rightness" of the suicide. They state, "Although the act of suicide may be substantially autonomous, it may not be right if it will seriously affect the interest of others. For instance, the suicide of a man without a fatal illness who is the only breadwinner in a family with three young children will cause serious harm," (Leikin & McCormick, 1991). Therefore, they suggest that Henry's objective worth or purpose is less than that of someone who is more invested in the lives of others; as a result, Henry is more justified in ending his life than some others. This viewpoint can also be extended to those who aren't as direct in their approach of disregard concerning their illness, such as those who do not search out an option to slow the progression of their condition. While this is a very controversial perspective (one that I do not share), from a utilitarian viewpoint, it can be justified relatively easily. However, they also believe that Henry should be empowered to make this decision, and all caretakers should aid in his departure from the world by making it as comfortable as possible.

In my own opinion, people who make the decision to live their lives recklessly because of a terminal or ultimately life-threatening illness should not be persecuted. Simply because someone believes that he would act differently in a given situation does not mean that he objectively knows what would be best for others. Perhaps by behaving without regard for their disorder, these individuals feel that they are fulfilling a larger purpose, whatever that may be; why should anyone else criticize this decision, when they

are not (nor will they ever be) in the exact shoes of the individual making these difficult and important decisions? There is little doubt that these instances elicit specific “knee-jerk”-like reactions that immediately prompt outside individuals to evaluate what they would do in that situation. However, I believe that these judgments should be reserved because no one can, with certainty, know what the trials are that others face; what’s more, since perspective is subjective, criticizing that of others is not logical, in my opinion.

## Service in Terminal and Life-Threatening Illness

### SERVICE

Each day, people around the world engage in service activities of all varieties. Many insist that they are “selfish” because they like the way that helping others makes them feel. There is sometimes a cathartic power to doing service—this may be seen in court-ordered community service. It is as if, as a society, we are saying that criminals should do penance for their sins. For the sake of this work, however, service means working toward bettering the lives of others, regardless of personal motivation. This may be engaging in volunteer work in which the outcomes of the service are never really fully seen. On the other hand, it may mean leaving a legacy behind for one’s family, or knowing that a group of people is able to effectively function in an autonomous and efficient manner. Overall, service fosters a largely relational connection, one that is often the source of the meaning-making systems of those who are contemplating the end of their life.

### CASE STUDY

Growing up in an extremely turbulent household as a child, Danny’s family was perhaps not the most well-equipped to deal with three boys. His father left his mother and the family when he was around six years old and as a result, his mother, Rita, was forced to work two jobs to support the three children. In order to provide for her family, Rita often gave up sleep and food. However, despite their minimal worldly riches, she tried to

instill a strong sense of spirituality in her boys, with which she hoped they would be able to conquer any obstacles that presented themselves.

Danny, however, later developed a strong feeling of repulsion from his church after being molested by a male neighbor with whom he had been very close. This event forced him to ask, “Why me?”, a question that did not coincide with his religious paradigm at the time. This began a long, arduous journey of self-loathing, reflection, and questioning, which ultimately led him to abandon the church and leave his home when he turned 18 and turn to drugs and alcohol to numb the pain that he had been trying to repress. In order to support this newfound habit, Danny began prostituting, eventually contracting Human Immunodeficiency Virus (HIV) due to his high-risk exposures that, over time, leads to the development of Acquired Immunodeficiency Syndrome (AIDS). In AIDS, a person’s CD4 T-cell count is below  $200/\text{mm}^3$  of blood; average is between  $500\text{-}1,800$  CD4 T-cells/ $\text{mm}^3$  (Public Health Service Centers for Disease Control and Prevention, 2007).

One day, though, Danny saw a cousin who told him that his mother had deteriorated quite a bit since he last saw her, and was now suffering from severe arthritis and was restricted to a wheelchair. Additionally, she had no one to care for her. Upon hearing this, Danny decided to suspend his current lifestyle and return home. While there, he cared for his mother extensively, doing everything in his power to help ease her discomfort and promote her well-being and happiness. He sincerely enjoyed doing all this for his mother and knew that alleviating some of her suffering was a productive and worthwhile use of his final days; the knowledge that he was able to reciprocate even a

fraction of all that his mother had done for him and his brothers during his upbringing was enough of a reward.

Despite his altruistic motives, Danny's condition worsened appreciably following his time with his mother (possibly even as a result of this time, because he likely over-exerted himself while he worked to improve her living conditions and quality of life). He told his mother of his illness and of his previous lifestyle and finally went to the doctor upon developing Kaposi's sarcoma, a telltale sign of HIV infection in which the connective tissue develops bluish-red tumors that manifest on the skin, often in readily observable areas. Interestingly, treating the cancer is not known to affect the prognosis of the AIDS virus in any way; ultimately, the amount of viral load that a patient has is the single best determinant of mortality from the virus, as it is what affects the concentration of CD4 T-cells. These tumors can even return after treatment, which is a component of the illness that effectively highlights how staggeringly compromised the immune system may become (Dugdale III, 2012).

After the revelation that Danny's health was beginning to fail, Rita began to reciprocate the care that he had recently given her. She cooked for him, did his errands, and even tried to keep him entertained. Though Danny was now on the other side, with his mother helping *him*, he still felt that their relationship was an essential aspect of both of their lives, especially with respect to their illnesses, and knew that he was not a burden; rather, his mother needed him just as much as he needed her. Their roles had shifted, and remained in this new conformation until Danny finally died. Overall, both Danny and Rita saw the other as a primary reason for continuing their own battle with

their respective illnesses, offering each the motivation and incentive to continue the difficult battle.

## ANALYSIS

This story is taken from Karen Wyatt's exposure to helping patients in hospice care in her collection *What Really Matters: 7 Lessons for Living from the Stories of the Dying*, in which she offers ways that we may enrich our own lives through examples of those who have been to the edge of the metaphorical cliff (2011). The book centers around the idea that those who are going through the dying process are more able to reflect on their own personal experience and better able to offer useful advice that may be derived from grand successes or even failures and regrets. Concerning the importance of giving yourself to others in terminal illness (but also in life), she states:

When we have plummeted to the depth of our suffering and faced it openly and honestly, we must then begin to learn [to]... "Let Your Heart Be Broken," which is the challenge to experience true Love. When we truly love another, that act results in the opening of our hearts so that we can achieve greater depth, compassion and growth. (Wyatt, 2011, 27)

The story of Danny and Rita effectively illustrates how important working for and with another while one comes to reconcile the gravity of his or her illness can be; ultimately, this type of relationship may even possibly become an substantial component of one's meaning-making system. When this is the case, the relationship must be dynamic, as was the case for Danny and Rita, in order for the individual suffering from the illness to be able to relinquish some control to the family or individual who cares for them, without it



affecting his primary meaning-making paradigm, since he may no longer feel that he is able to contribute to the person or family.

The idea that some, or even a majority, of one's personal meaning in life may be rooted within another person is actually a rather pervasive one. As previously mentioned, in his memoir and psychological analysis of his time spent in concentration camps during World War II entitled *Man's Search for Meaning*, Viktor Frankl showcases his psychological theory logotherapy, the idea that the single, strongest motivating factor in a person's life is his or her drive to attain some idea of meaning, in order to make some sort of sense of his or her life. In describing this, Frankl asserts:

...The meaning of life always changes, but...it never ceases to be. According to logotherapy, we can discover this meaning in life in three different ways: (1) by creating a work or doing a deed; (2) by experiencing something or encountering someone; and (3) by the attitude we take toward unavoidable suffering. (Frankl, 2006, 111).

For those who choose to attain their meaning primarily via their relationship with family or by giving oneself to others in another way, the second way of finding meaning is probably most applicable.

In this type of relationship, love is often the primary manifestation of the meaning placed in the relationship. Frankl defines love as the ultimate togetherness; rooting oneself in another in similar fashion to the relationship that Rita and Danny eventually shared. Perhaps something about this type of deep love transcends illness, and gives one

the strength to either continue or to let go when the time is right and take solace in the fact that the person for whom they have been living is in a good place.

Though the ability to use his life as a vector for familial improvement may sound appealing to an individual with a terminal or life-threatening disease, just the fact that he is afflicted by a disease, disorder, or deficiency may have a negative impact upon the family as a unit. As a result of this “double-edged sword” dynamic between the ill individual and his family, the person with the illness may feel guilty about imposing this extra strain on the family. Additionally, he may actually over-assert himself, trying to compensate for the extra difficulty that is placed on the family, and continue to attempt to feel like a valued member of the family, rather than just being an economic, emotional, and even sometimes physical burden.

When someone becomes ill, he personifies the final element of a psychological theory called the “medical model,” which essentially states that the psychological and sociological pathology exhibited by an individual is treated effectively the same way as in cases in which a disease displays itself physiologically. This final element is called the “sick role.” Susie Scott, a professor of Sociology, defines this as “a set of social roles and expectations attributed to those who are ill, their doctors, and other people in their everyday lives,” (Scott, 2009). The four major components of the “sick role” are:

- (1) The individual is granted legitimate withdrawal from their usual social responsibilities...and exemption from moral blame for their condition, but only if
- (2) they in turn are prepared to seek help from a medical practitioner and to show a desire to get better.
- (3) The doctor is expected to treat the patient in a neutral,

objective manner and assist his or her transition back into normal social life [and]  
(4) ... family and friends are expected to indulge the individual in their retreat  
from interaction, on the understanding that they will soon come back into play.  
(Scott, 2009)

As one might imagine, this is somewhat modified in individuals with some sort of terminal illness. Despite this, much of the sick role remains the same, if it is not amplified; for example, the family and friends of a person with a terminal illness might make excuses for others (or even for themselves) regarding the behavior or lack of participation of the ill individual. Because of this cultural and psychological difference that is displayed in those who are sick, it may be easy for some to have to alter their meaning-making paradigm. Since it is now socially acceptable to not support one's family, an individual who puts much of his worth or meaning in what he is able to give his family may have extreme difficulty navigating the world in which he is now the primary focus. On the other hand, this newfound culturally- and socially-acceptable incapacitation may even empower the sick individual to maintain his current form of support to the family, allowing his sense of meaning and purpose to be maintained without any modification.

However, despite the good it may do with respect to a meaning-making system for the person suffering from an illness, the news of the diagnosis of a life-threatening illness can be devastating to a family. Many cases of individuals being left by spouses, or families being forced to declare bankruptcy exist, and the hardships that these diagnoses entail are often extremely trying on people in already exceptionally trying circumstances.

In fact, one study found that, of a population survey of 22 individuals with a diagnosed terminal illness in India, in roughly one-third of these families the spouse was forced to change his or her working habits, nearly half had children that were forced to miss school due to their parent's illness, and all respondents reported that they had such financial hardship as a result of the illness that they were forced to sell some of their assets in order to afford the combination of treatment and the continuation of everyday life via living expenses (Emanuel et al., 2010). Obviously, this kind of dramatic economic stress could largely negatively affect even the most well-off of families (especially in nations with privatized health care, where many medical expenses come from an individual's income). While the family itself may serve as an incredibly uplifting entity, it may also be exhausting to be positive and supportive when each member of the family also has his or her own grieving to do regarding the prospect of losing a close family member.

Because our collective idea of death as a culture has transformed so dramatically over the past 200 or so years, it is difficult to imagine simply "letting" someone die; people constantly feel compelled to find a way to "save" people's lives, regardless of whether or not this intervention will prove to actually better an individual's quality of life. Whereas people used to die relatively quickly following the diagnosis of a terminal illness, we are now able to keep them alive in a sort of exaggerated limbo, wherein they know they will die soon and must live with this knowledge (and, for most, worsening symptoms) until this time finally comes. In the United States, as in India, the costs that medical treatment in end-of-life care incurs are often extremely substantial, and even

crippling to some families. Up to one-third of Americans with chronic illnesses say that they have had difficulty paying for their treatment, and 12% were not able to afford basic necessities such as food and shelter (Donley and Danis, 2011). What's more, it is estimated that had the health care reform bill not passed, health care would reach a staggering 49% of the gross domestic product of the United States by 2082 (Donley and Danis, 2011). Despite this, the country that spends the most on health care each year in the world (beating out all other developed nations) is the United States.

Further, the drawn-out grieving and death phase is producing something Dr. Joseph Nowinski is calling "new grief," (Nowinski, 2011). Much of this "new grief" actually involves the family of the individual with the terminal illness as actively as the person who is afflicted by said illness. In the first stage, entitled the "unity" phase, the family bands together and focuses on the individual with the illness. All other obligations and priorities are set aside, and the sick person gets the majority of the attention. It is in this stage, however, where those who choose to place a sizable amount of their personal meaning or purpose in their ability to help their family or others are often conflicted since they are not actively helping those around them; rather, those whom they care about are taking considerable time from their lives to help the individual. Thus, this may actually worsen the afflicted individual's resolve since they might feel like a burden on the ones that they love. On the other hand, if this individual is very far along in the dying process, they may show considerably less reluctance, as there is little that they may be able to do for themselves or anyone else by that stage in their terminal, chronic, or life-threatening illness.

In the next stage of “new grief,” stress may manifest itself in different ways for each member of the family, such as missing obligations or skewing priorities or even bringing up past issues that were previously destructive to the family. Sometimes these stressors can have a negative effect on the family and its dynamic, as well as the individual with the disease (Nowinski, 2011). Again, this backlash may negatively affect the meaning-making paradigm of the person with the illness because it is difficult to see those whom one puts so much into (including his own self-worth, in many cases) suffering as a result of the individual who is supposed to be contributing *to* his family’s lives in a positive manner!

Finally, however, Nowinski suggests that this “upheaval” is actually a completely normal and healthy way of dealing with the knowledge of a dying family member. Each member of the family is forced to reevaluate his or her role in the familial unit as a result of the onset of the illness, including the afflicted person. The different feelings of guilt, denial, sympathy, greed, and jealousy are all somewhat pervasive at different times for different people in different roles in the family as they attempt to reconcile their relationship with the person who is dying (Nowinski, 2011). While the previous two steps may have had a negative impact upon the dying individuals if they have a considerable amount of their meaning-making system comprised of family, the final stage (including upheaval) may help to add perspective and a sense of complacency in the way that they will leave the world, probably proportional to the strength of the individual’s relationship with his family. Dr. Nowinski cites the common adage “every crisis creates opportunity” to highlight how much stronger the family dynamic can become, not in spite of, but

*because of* the diagnosis of a terminal illness in the family. Knowing that previous conflicts have finally been ironed out, that the family is capable of continuing productively without the ill individual's presence, and knowing that, though their time together was fleeting, he had an appreciable impact on the current and future lives and decisions of those whom he cares about is often a very comforting and healthy way to reconcile the difficulty that both death and this meaning-making paradigm bring. Additionally, the person utilizing this meaning-making system probably also has a very strong and resilient relationship with his family to begin with, so he might be better equipped to reconcile his own mortality with such a solid support system, one that only a very close and connected family may provide.

Beyond the love that Frankl suggests, however, I believe that an analogous interaction can be seen when someone copes with his illness by giving himself to others through service. Whether this means supporting a neighbor, donating money to charity or a religious organization, or actively volunteering with a nonprofit organization, I believe that one is capable of attaining a sizable sense of meaning from these types of service. Perhaps, using the paradigm provided by Frankl's definition, this type of meaning is a synthesis of both "experiencing something or encountering someone" *and* "the attitude we take toward unavoidable suffering." A person may engage others while also alleviating some of the suffering that is rampant throughout the world, thus providing a strong sense of motivation and meaning, as well as the knowledge that one's continuation in the battle with his illness is worthwhile, as well as the labors of their life through his diagnosis of illness. In the vein of Dr. Wyatt's book, the dying have much to offer the

living via anecdotes and other forms of support and advice, but the living also have much to offer those who are dying in that they may serve as a sense of stability in the dynamic world that is terminal and life-threatening illness.

Overall, service as a meaning-making paradigm has the potential to be one of the more healthy options of coming to terms with a life-threatening diagnosis. Though it may be difficult, depending on the individual, to reconcile the shift from being a primary source of resources for one's family to becoming a burden in many respects, this paradigm offers the sufferer reassurance in the form of familial or community-based stability. The knowledge that one may leave the mortal world while his or her surroundings are intact and highly functional may ease the transition into death for the ill individual, providing an overall less turbulent dying process.



## Spirituality in Terminal and Life-Threatening Illness

### SPIRITUALITY

Faith and spirituality are pervasive elements of daily life for many humans. Many people engage in prayer, meditation, and/or communal worship services daily. These different methods of getting in touch with the spiritual aspect of one's life are often extremely helpful as one encounters stressors. Following natural disasters, people often rush to churches, mosques, synagogues, and other spiritual houses to benefit from the healing energy of their community and higher power. Comparatively, there is little difference, on an individual scale, between a natural disaster and the diagnosis of a terminal or life-threatening condition; often the latter is much more powerful and destructive. Similarly, many with terminal or life-threatening conditions turn to their faith or spirituality to aid them throughout the time that they are ill, regardless of their apparent prognosis. Throughout this section, the importance of spirituality as a meaning-making system will be highlighted; given my background, this will be shown from a largely Judeo-Christian understanding of faith and spirituality.

### CASE STUDY

For Reverend Thomas Hosinski, fear was a strong presence in his life following his diagnosis of Hodgkin's lymphoma. This relatively rare form of lymphoma affects lymph tissue, like that found in the lymph nodes, spleen, and liver. This cancer generally affects younger individuals (usually between the ages of 15 and 35) and has one of the

most promising prognoses of all forms of cancer, boasting nearly a 90% cure rate when the correct methods of treatment are applied and maintained (Chen, 2012). Despite this seemingly positive outlook regarding the disease, after one of his lymph nodes was removed for biopsy, Fr. Hosinski stated, “The possibility of my imminent death filled me with regret, with longing for life, [and] with a withering fear,” (Hosinski, 2000). Upon the threat of death, most people question the life they have lived, including the decisions they have made and the goals that they have not achieved. Even though all these things tend to be relatively commonplace as one comes to terms with their diagnosis of a terminal or life-threatening illness, Rev. Hosinski still felt helpless, alone, and immobilized by fear.

As he continued to come to the realization that his life might soon end, Rev. Hosinski remembered, “All the blessings in my life, and tried to convince myself I could be at peace because I had done what I could to build God’s kingdom. But it was useless—the fear still dominated me,” (Hosinski, 2000). Because of the fact that many struggle with not being able to reconcile the idea that God *could* do something but would not, Rev. Hosinski worked to navigate this traditional idea of religion and view of God. Ultimately, however, he came to decide that “the ambiguity of our experience implies, I believe, that God’s power is actually self-limiting because of the nature of the universe God chose to create,” emphasizing that God’s omnipotence and respect for our free will in combination is what empowers Him to not interfere with our lives (Hosinski, 2000). He believes that God simply allows things to happen, and will be there for us when we

deal with things that we believe we cannot face alone, and may be seen through various human acts.

Throughout the time that Rev. Hosinski spent in treatment, he developed a mantra that aided him when times were tough and he did not feel like continuing: “God is with me, all will be well,” (Hosinski, 2000). Because he saw God not as an overarching withholder of power, but rather as a compassionate figure that could not intervene, Rev. Hosinski stated that “my faith in God... did not cause me to pray to God to miraculously remove my cancer. Instead, if focused on God’s continual sustaining presence. I sought to open myself to that healing, saving divine presence,” (Hosinski, 2000). Through the lack of hope for intervention by God, Fr. Hosinski was able to focus less on the fairness of his condition and more on deepening his connection with God and on the fortification of his own resolve. However, while he had found a way to cope with this fear, he certainly had not overcome it. This was especially noticeable to him when he started chemotherapy; as he lost the ability to taste and his hair fell out, all he could do was repeat his mantra: God is with me, all will be well.

One of his friends gave Rev. Hosinski hope and helped to substantially reduce his feelings of fear. This friend, named Jeff, took him to and from his chemotherapy appointments and did many of the errands that Rev. Hosinski was unable to perform himself and effectively served as a manifestation of the ever-loving and ever-healing presence of God, reinforcing his healing mantra (Hosinski, 2000). Additionally, this friendship helped to limit his feeling (and the feeling that is common in individuals upon whom are thrust the “sick role” when they hear their diagnosis) that:

Illness cuts the afflicted off from normal life and makes them feel like they have been exiled. Serious illness pushes the patient to the margin of life, a lonely and fearful place in which every stray remark is savored as a lifeline to the ordinary world. (Hosinski, 2000)

In the sick role, individuals often feel reevaluated by others, something that can feel extremely alienating; luckily for Fr. Hosinski, his friend was there to help curb this negative feeling. However, in an unfortunate twist of fate, following Rev. Hosinski's remission from his cancer, his friend was diagnosed with cancer and died soon after (Hosinski, 2000).

In retrospect, Rev. Hosinski has been able to reconcile these events by seeing God as personified in people, rather than through grandiose acts. He states that he has felt God's compassion through:

Jeff's love and care, through the doctors and nurses who cared for me with such dedication, through my friends' concern and prayers, through the gentle touch of my cats' paws, [and] through the ordinary extraordinary beauties of daily life that we so often take for granted. (Hosinski, 2000)

He goes on to say that he can equally feel the *lack* of God's presence in those who do not show compassion, because our actions so heavily reflect the presence and power of God (Hosinski, 2000).

He concludes this retelling of his struggles with this disease and the idea of being ill in general by saying:

We have within us a deep power to overcome fear. I understand that power to be the presence of the God who brought each of us and the universe into being, who is constantly present with us, who suffers with us, who saves us. This power and life, the wellspring of our lives, is a constant source of hope and serenity, even in the face of death. It is the power of love; and we are blessed when we allow it to live and act in us. (Hosinski, 2000)

Here, it is clear that, despite the challenges that life (and especially terminal and life-threatening illness) presents, it is Rev. Hosinski's interpretation that God may be seen in all things, and is also a resource that can support each individual as necessary. While He will not interfere with one's free will (or, rather, the progression of events that occur on earth), God's compassion is infinite and He yearns for its consumption.

#### ANALYSIS

While Rev. Hosinski's story is unique in many respects, the idea that he endured the traumatic experiences necessary to survive is not particularly out of the ordinary. Additionally, it is not especially unique that he attributes recovering from Hodgkin's lymphoma to his relationship with God: many people overcome illness with this approach, and the majority feel that their relationship with Him is stronger, and that they, too, feel like stronger versions of themselves. In fact, over 90% of Americans say that religion and/or spirituality are essential components in their lives (Yanez et al., 2009), meaning that one would expect these individuals to rely heavily on religion and spirituality to cope with a terminal or life-threatening illness.

Much of his ability to endure the time with his illness was because of Fr. Hosinski's ability to make the distinction that an omnipotent God can also be a self-limiting God. While now a relatively common outlook, during Jesus' time, it was largely unheard of. During this time, it was believed that God bestowed illnesses upon people, often as a result of sin, a theory called the theological (or moral) explanation for illness (Sanford, 1992). Today, this view is considerably less popular, since many people have a difficult time reconciling this idea with the ways in which they live their lives, and also with their current understanding of God, though it still exists. In fact, the Greeks were the first to develop some semblance of a scientific theory of illness; they worked to understand human anatomy via dissections and were the first to discover that the circulatory system is an integral aspect of one's well being through its interconnectedness (Sanford, 1992). This presents an interesting dichotomy, since the Greeks also had a largely moral understanding of illness while grappling with the scientific theory. It is because of this revelation (and, of course, further work within the medical field) that we now accept the scientific model of illness, thus allowing for Fr. Hosinski's interpretation of God and the ways in which He works.

Interestingly, in her book *What Really Matters: 7 Lessons for Living from the Stories of the Dying*, Dr. Karen M. Wyatt agrees with this common approach stating, "...we exist as physical beings precisely for the purpose of learning certain spiritual truths during our time on Earth," and that "in the latter days of life, a gradual shift in focus must occur, away from the pursuits of the physical world toward the truths of the spiritual realm," (Wyatt, 2011). It is with this sentiment that one may see that though God

doesn't *give* someone an illness, He may still expect that the individual afflicted with said illness will work to better his relationship with God, or enrich the lives of others through his story, or whatever else God intends. In a sense, since we all experience some form of suffering in our lives, we may be tasked to overcome this suffering, and become better people as a result of it. When viewed in this way, it is not surprising that many individuals with terminal or life-threatening illness choose to find meaning in their relationship with God.

In her work with individuals in hospice care, Dr. Wyatt has found that many commonalities exist within people in these situations. Like Rev. Hosinski, she also sees a common theme of fear that runs through humanity, even those who are not afflicted with a chronic, terminal, or life-threatening illness. The anxiety spurred by death can affect all of us, especially with the ever-present reminders of it that constantly surround us. She supports this assertion by insisting:

To our detriment, the fear of death has consumed us and led us to expend increasing effort and healthcare dollars toward preserving life at all costs. For example, approximately 25% of the annual Medicare budget is spent on aggressive, life-sustaining care during the final month of life, much of which is futile and may actually prolong suffering rather than enhance life. (Wyatt, 2011)

As exemplified in these statistics, fear can be an extremely expensive habit, one that may even worsen an individual's quality of life.

If she is correct about fear being the primary component that serves to fuel the aggressive end-of-life care that is pervasive in this country, and this substantial amount of

money and resources are spent as a result of a fear of death, then we are a culture that promotes futility, since we will all die at some point. However, she continues by saying that as we begin to come to terms with our impending death, we eventually stop fearing the unknown. This may be accomplished through spirituality, and one's relationship with God. Dr. Wyatt goes on to say that the essence of spiritual growth is "to employ all that has been given in this life (including both the positive and the negative factors), manifest the greatest potential available, and recognize that everything, including the Self, is sacred," (Wyatt, 2011). Using these (admittedly abstract) tools, one may work to overcome the fear that is inherent in dying.

One theory of the thought and existential progression that occurs prior to death for those who do not choose to find meaning in their spirituality (or via some other means) is the idea of disengagement. Individuals following this path are described by others as "withdrawing their attentions from the affairs of the wider world, including family and self-care, appearing to surrender to tiredness, weakness or dependency in general," (Kellehear, 2009). However, the stress that is certainly placed on close family and friends of individuals who take this path to death may be alleviated if the individual chooses to not take this path at all, or to only withdraw somewhat. One way of accomplishing this is by fortifying one's relationship with God—this will result in less of a sense of detachment from one's life and the world around him, as the individual afflicted with the illness will strongly feel that he has a reason to continue to live.

The author of the book that details these different paths to dying and ultimately death, Allan Kellehear of *The Study of Dying: From Autonomy to Transformation*, states



that he believes that these paths help people cope with uncertainty (Kellehear, 2009). These different paths may serve as types of defense mechanisms against the unknown—though they are not as intent on protecting the individual from the truth as traditional mechanisms. Rather, they serve to allow individuals to come to terms with their illness when it is possible for them to do so, and also as we change as individuals and as a society; they may effectively be termed coping mechanisms. Other types of themes regarding death include that of personal control, linearity, fluctuation, disintegration, and others (Kellehear, 2009).

However, I believe that a solid meaning-making system, like the one exemplified by an honest and dynamic relationship with God, also helps people to cope with life's (and whatever follows life) uncertainty, even with the knowledge that one has a terminal or life-threatening illness. Knowing that "God is with me, all will be well" may be extremely comforting in times of despair regarding the state of one's family, friends, estate, and belongings. This relationship can also help to provide hope to the afflicted individual; this hope may serve to counter some of the uncertainty that he may feel, but it also may help to repel the persistent feelings of fear that were described by Fr. Hosinski, since the consistent and strong relationship with God that is capable may be appreciably empowering.

Despite this hope and alleviation of negative emotions, there is little doubt that those who are diagnosed with terminal illness are often inconvenienced by their disorders, especially as they progress toward death. However, in one of the "7 lessons for living from the stories of the dying," Dr. Wyatt encourages those who have a chronic, terminal,

or life-threatening illness to “embrace the difficulties, face them head-on with courage and equanimity, and create something beautiful from the ruins,” (Wyatt, 2011). In this case, she uses Jesus’ trials prior to and throughout His crucifixion to highlight the grace and courage with which we all can approach death and dying, including the process of leaving behind loved ones. What’s more, Dr. Wyatt even would say that suffering is a necessary aspect to life, because becoming a better person requires a certain amount of sacrifice. Under this foundation, those who are diagnosed with a life-threatening or terminal illness from an early age would probably be more adept at navigating suffering and loss, as they must come to terms with their condition much earlier than the average person (if they even get that luxury).

Other types of suffering may be mainly psychological. Up to 58% of individuals with cancer display symptoms of depression, and 38% display diagnosable depressive symptoms (Nelson et al., 2009). Thus, the terminally ill have a much higher risk of developing depressive symptoms and other forms of psychological disorders, such as anxiety disorders. As previously stated, those individuals with life-threatening illness are more likely to be diagnosed with depression than members of the general population. However, in their study, Nelson et al., found that while an individual’s level of religiosity and/or spirituality does not significantly affect the prevalence or severity of depressive symptoms, an individual’s sense of meaning and peace do seem to have a large effect (2009). This means that those who use their relationship with God as a way to attain personal meaning are more likely to not have these symptoms, adding extra incentive for the 90% of Americans who profess that religion and/or spirituality are an integral aspect

of their lives. Another study found that this peace and sense of meaning can also help to contribute to favorable adjustment overall by cancer patients (i.e. they spend less time mourning, are more positive concerning possible remission, etc.) (Yanez et al., 2009).

In a personal interview with Fr. Hosinski, when I asked what aspects of the relationship with God are most helpful in coping with terminal illness, he replied that God's presence as a result of suffering was extremely comforting, reasserting his viewpoint that "God is with me, all will be well," (personal communication, Hosinski, 2012). He went on to say that, in his experience, upon the administration of last rites, the individual is almost always overcome by a feeling of peace because of the "conviction that we're being taken to another life," (personal communication, Hosinski, 2012). Because many people have a consistent sense of anxiety following the diagnosis of a terminal or life-threatening illness, many may also die with this same strong sense of anxiety intact. The administration of last rites can substantially help to alleviate this anxiety. Following this assertion, I asked him if these aspects can be found in other things, or if a relationship with God is a necessity to find them; to this, he responded that a modified version of the peace that is practically synonymous with the anointing of the dying may still be present, as the individual who is dying actively reflects upon his or her life and comes to terms with the ways that things have unfolded. Additionally, since he believes that people can serve as vectors for God's love, the healing and comforting presence of God may be present in the devotion of family and friends and different kinds of compassionate human contact (Hosinski, 2000). What's more, the humor that family and friends may offer is essential—he states that it is one of the main things that helped

him to get through his illness and treatment (Hosinski, 2000; personal communication, Hosinski, 2012). However, he also emphasizes that personalities vary considerably among those who are dying and, as such, each person may feel this peace and manifestation of God's love in different ways and to different degrees, depending on their prior experiences and current knowledge base (personal communication, Hosinski, 2012).

The sometimes lengthy process of dying can be rife with deep experiences of suffering as individuals cope with the loss of their conveniences, families, jobs, and all other aspects of life. Surprisingly, for some, this suffering can also be a predominantly spiritual experience. For those who do not come to terms well with their mortality, it may be very difficult to do what Rev. Hosinski was finally able to do: reconcile the idea that God may be able to help one's condition, but does not do so. Many spend their remaining days angry with God for His "choice" to put them through the trials of the disease with which they are afflicted, and may feel cheated regarding their circumstances. Surprisingly, though, "when emotional and spiritual discomforts are present they can intensify the experience of physical pain, making it much more difficult to treat physical discomfort with conventional methods," (Wyatt, 2011). Thus, this anger with God can ironically exacerbate one's condition, increasing the level of suffering that one feels physically, emotionally, and spiritually.

In my interview with Fr. Hosinski, we also covered the issue of those who are angry with God prior to their actual death. In this case, he said that the best way to approach these individuals is to "convince them that God didn't 'do' this to them;" rather, since God has given us legitimate free will, things really do just happen (personal

communication, Hosinski, 2012). It is our responsibility to react nobly to these challenges and maintain what makes us ourselves by personifying God's love through our actions. He also stated that emotion is largely the force in charge in these scenarios, rather than rational thought. He even suggests that this is perhaps only a stage in the dying process that individuals suffering from these illnesses typically overcome with time (personal communication, Hosinski, 2012). Once the individual finally gets past this "phase," he may be better equipped to take on the dying process directly, and may have finally reconciled the possibility of fear that is widespread among those who are dying.

Ultimately, the use of spirituality or religion as a primary meaning-making system is an act that, given a relatively dynamic understanding of God, is capable of effectively aiding an individual in the process of dying, or at least coping with one's illness. This paradigm is one that has the potential to be incredibly comforting for two reasons. First, individuals suffering from a terminal illness may take solace in the fact that their life was worthwhile because they were efficacious vectors for God's love and message. Next, the assurance that life does not end at death can assuage feelings of fear and regret for ill individuals. In conclusion, for those who practice religion or who would describe themselves as spiritual, this paradigm offers legitimate benefits, if applied correctly and with an open mind.

## Conclusion

As Viktor Frankl (in conjunction with Maslow) suggested, and as I have asserted throughout this thesis, the idea of meaning in one's life is an incredibly important one. Without it, we may simply meander through life and its numerous experiences completely unaffected; however, *with* a sense of meaning, these experiences can shape our outlook on life, the ways that we solve problems, the people with whom we interact, and especially the decisions that we make (and by extension, the things that we value). Within logotherapy, Frankl nods to Maslow by somewhat integrating the idea of the hierarchy of needs, implying that the needs that are more primitive must be satisfied prior to moving up the hierarchy. However, Frankl isn't as ambiguous regarding self-actualization as the apex of the hierarchy of needs; instead, he interprets this idea *as* personal meaning. He insists this, stating, "Man's search for meaning is the primary motivation in his life and not a "secondary rationalization" of instinctual drives," (Frankl, 2006, 99).

Throughout the course of this thesis, the ultimate goal of my investigation into the lives of those who are coping with terminal or life-threatening illness was to determine if some ways of establishing or modifying individual meaning were strikingly better than others, especially among the meaning-making systems that I have suggested. By "better" I mean that perhaps the methods utilized allowed the individuals to be more resilient mentally and emotionally, or better able to retain a sense of identity despite the affliction.

Further, I strived to determine whether or not there was an unspoken archetype for how one “ought” to navigate life with a terminal or life-threatening illness; a direct and specific path that lends itself to *not* seeing this type of illness as such an impediment in one’s life.

Interestingly, a study conducted by Lundman and Jansson found meaning-making paradigms that were similar to those that I have proposed (2006). In the interviews they conducted with individuals with chronic or ultimately terminal illnesses, Lundman and Jansson found that the meaning of living with a long-term illness could be divided into several themes. The themes that they found were “loss and uncertainty threaten everyday order,” “learning one’s capacity and living accordingly,” “maintaining fellowship and belonging,” “having a source of strength,” and “building anew,” (Lundman & Jansson, 2006). Each of these constructs loosely fits into the themes that I have suggested; for example, the idea of “loss and uncertainty threatening everyday order” is similar to the idea of fear being inhibitory toward one’s goals or living out one’s life in the way that he would like. Further, the themes of “maintaining fellowship and belonging” and “building anew” both allude to the concepts of finding meaning via spirituality or through relational service. To some degree, even the idea of disregard (or denial, or defiance) can be supported through Lundman and Jansson’s finding of the theme of “having a source of strength,” since the pride in one’s autonomy may be the strength with which one navigates through his experience with terminal or life-threatening illness. Because these

are relatively universal characteristics, one would expect these to largely remain conserved over time and geographic area.

Thus, since these paradigms are obviously legitimate vectors through which one may attain personal meaning, the question that arises, “Which is the best?” Obviously, after discussing the four distinct perspectives that I have suggested, there is not much literature on those who allow their illnesses to take control of their lives; nor is there a substantial amount written about those who disregard their illness (either through denial or through defiance). However, there is an abundance of data that suggests that those who come to terms with their illnesses via relational outreach, service, or spirituality (or even a combination of all these) often feel more at ease as death approaches because they feel that the world they are leaving is an ordered one. Additionally, these approaches leave the individual with a feeling of being in control; thus, individuals may feel comfortable in departing from this world with the knowledge that they have crafted lives for others that are healthy and persistent, whether through spiritual vitality, through setting the precedence for positive family dynamics, or through some other means.

However, if there is one thing that I have learned throughout this exploration, it has been that the experience of living with an illness is a highly personal one. No two individuals experience exactly the same symptoms to exactly the same degree. Further, the relational dynamics at play in a person’s life will certainly be different than that of another person. As a result of this diversity of experience and perception, it is impossible to say that there is a definitively “correct” method of making meaning as one goes through the process of dying. As Frankl said with respect to personal meaning making in



general, “This meaning is unique and specific in that it must and can be fulfilled by him alone,” (Frankl, 2006, 99). Thus, even the paradigms that I have suggested are little more than approximations of the true meaning-making systems that are being utilized by individuals fighting terminal illness.

While I do not believe that there is an objectively “right” way to find meaning in life following the diagnosis of a terminal illness, I do think that there are more and less virtuous ways to do so. In alignment with the Jesuit tradition, the question, “How ought we to live?” conveys this implication of virtuosity. In this case, I believe that the “ought” may be coping with one’s terminal or life-threatening illness through service of some sort or through spirituality. These methods improve the world and are, without question, more positive overall than the other two methods. However, I do not believe that those who deal with their illness using fear or disregard of some sort deserve to be condemned. While those two methods may seem more selfish, ultimately what matters most is how effectively the paradigm works for the person. As ill individuals, they have no obligation to anyone but themselves to evoke a sense of meaning, so however they wish to do so should be fine, and they should be free from judgment for the ways in which they decide to live out the remainder of their days.

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