

## **SUFFERING IN SERIOUS ILLNESS**

Understanding the role of personal identity

By

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### **INTRODUCTION**

She asked me to help her die! I told her that I couldn't do that because I am a physician who has sworn by the Hippocratic Oath to treat "for the benefit of the sick according to my ability and judgment." I then reviewed in my mind the clinical situation. She was in her 70s and had metastatic pancreatic cancer. Surgery had failed to cure her disease and her pain was very difficult to control. She had lived for 3 years with her disease, which was much beyond what would be expected. I asked myself whether it would be in her best interest to continue to live like this or whether it would be to her benefit to die prematurely but peacefully. I suspected that her desire to die had to do with some type of internal suffering to which I was not privy. Perhaps according to my oath I would be *benefiting the sick*, in my judgment, if I participated in her death. However, I never did assist her in her dying and she later told me "I am a good Lutheran." She was willing to live out the remainder of her life and accept the natural history of her disease.

Thus began my emotional and intellectual search as a physician to understand what medical school never taught me: that patients are more than biological models of disease; that patients are people who have emotions and fears; that patients may have secret dreams that may never be fulfilled when they are dying. It was apparent to me that I really didn't fully understand this element of patient care. I wanted to know why patients such as this one want to end their life, despite the most advanced medical treatment. It was my hope that if I could understand patient suffering in serious illness that I could provide more compassionate care.

Many major religions teach their adherents about suffering and the rewards that await them if they are able to endure. Unfortunately religious education is not part of many medical school curricula and patients and physicians may not be particularly religious or don't understand some of the more complex topics of their religion. I felt that the answer to the question of what suffering is and why it may occur in some patients and not others may be found in the field of philosophy. Philosophy addresses many areas that I felt might be relevant to this topic including the mind/body duality, personal identity, alienation, the problem of Evil, and phenomenology as a method of evaluating one's lived experience.

Traditionally, when a patient who is seriously ill expresses a wish to die, a physician will suspect that the patient is depressed and suggest psychiatric evaluation and treatment. However, there are many observers of this phenomenon from other disciplines, such as medical anthropology and the medical humanities, who feel that it

is a natural response when one is ill to express this type of distress. These illness symptoms are culturally derived and vary according to one's ethnography and biography and may have a moral or spiritual aspect.

Arthur Kleinman who is a psychiatrist and a medical anthropologist has written extensively on this topic, especially in *The Illness Narratives* (1988). He wrote that, "When the body becomes ill, we develop uncertainty that may lead to confusion, shock, anger, jealousy, or despair"(p.45). Arthur Frank, a medical sociologist, wrote in his moving memoir *At the Will of the Body* (1991, p.65) that:

Too few people, whether medical staff, family or friends, seem willing to accept the possibility that depression may be the ill person's most appropriate response to the situation.

Eventually the patient with a serious illness may just "give up" and thus accept that they will continue to decline. Once this mindset develops a patient's self-esteem is threatened and this may ultimately affect both their interpersonal and professional relationships. Thus, it behooves the physician to try to understand the origins of the patient's illness response.

To do this the physician has to begin to understand the totality of the patient from many different perspectives, not just as a biologic model of disease. Listening to a patient's and their loved ones' illness narratives may provide another view of their situation that would allow a better understanding of their suffering.

Both the patient and their caregivers construct narratives to help them make sense of the illness. The theme of these narratives may include such topics as heroism, cowardice, injustice, or remorse. Once constructed these narratives give coherence to their suffering experience. The plots of these narratives are drawn from one's personal and cultural experience and metaphor is one device frequently used as a means of communicating to others how they are feeling. These narratives frequently have a moral dimension and by attending to these moral issues one may begin to create a healing environment, even in the process of dying. Frank describes this scenario beautifully:

Someone who is dying - like the developing child, goes through stages of discovery, insight, and adjustment to constantly changing circumstances.

Personal struggle can lead to growth and dying well.

Family members and physicians frequently respond upon listening to these narratives with both empathy and sympathy which may help them to develop moral understanding not just about the patient but also about themselves.

In this thesis I will examine serious illness as exemplified by paradigm cases of AIDS, cancer, ALS, and Multiple Sclerosis. I will analyze how these illnesses affected one's changing identity over time (diachronic identity) based on a model of the *self* described by Galen Strawson (1997). I will look at the illness experience by examining the patient's description of pain and disability and how they both influence

one's psychological and bodily identity, and I demonstrated that one's suffering with a serious illness is best understood by looking at the significant changes in one's identity brought about by the illness.

Previously, commentators on suffering focused on the importance of pain or depression or dissolution of personal integrity as causes of suffering. This study is important because it shows that one's changing personal identity in serious illness plays a more important role in suffering than previously believed. This study also reveals the benefit of **phenomenological** analysis in understanding the experience of illness over the standard biological model. This technique also provides new and valuable insight into suffering that may help the patient to heal or to develop a transcendent response to the illness.

Although my primary goal is to look at the importance of changing personal identity to the suffering in serious illness, there derives from this analysis other concepts that may be useful. For example does unrelieved suffering lead to a desire for euthanasia or physician-assisted suicide in serious illness? There are also some insights to be gleaned about the growing distrust of traditional medicine and the increasing popularity of complementary or alternative medicine in the United States. However, while I may briefly discuss these issues they are not crucial to the argument of this thesis.

### **Definition of Terms**

Acquired Immunodeficiency Syndrome (AIDS): Infection with Human Immunodeficiency Virus with accompanying lethal immune deficiency markers, opportunistic infection, or Kaposi's Sarcoma.

ALS: Amyotrophic Lateral Sclerosis

Biopower: A term introduced by Foucault that refers to the use of technology for social control.

Disease: The unique cause of illness in the body of a sick person

Euthanasia: The practice of ending a person's life in order to release the person from an incurable disease, intolerable suffering, or undignified death (Beauchamp and Childress, 2003).

Illness: The subjective experience of the disease. "Illness talk tells of the fear and frustration of being inside a body that is breaking down" (Frank, 1991, p. 13)

Person: A human being with a certain moral status and certain capacities and has a sense of *self*. Has a sense of past and future and has values, and makes choices (Thomasa, Weistub, and Herve, 2001).

Phenomenology: An attempt to describe one's experience directly, separate from its origin and development and independent of causal explanations.

Physician-Assisted suicide (PAS): A patient's voluntary suicide with the assistance of a physician. The persons who die are themselves the ultimate cause of death; the physician merely assists. (Beauchamp and Childress, 2003)

Philosophical Materialism: A theory that matter alone exists. It denies the existence of minds, spirits, and divine beings.

*Self*: The awareness a person has of one's "ownness"; the cohesive characteristics of a person (Thomasa, Weisstub, and Herve, 2001).

Suffering: The physical or mental distress caused by illness. It usually is culturally determined and has a social context. It is a type of helplessness that occurs in silence and may lead to disintegration of the *self* (Morris, 1998, p. 201)

### **Limitations**

My observations are restricted to adults with four serious, life-threatening illnesses: AIDS, cancer, ALS, and MS. Children and adolescents have both a complex process of personality development and medical and emotional issues that exclude them from consideration in this thesis.

Another limitation is my selection of the paradigm cases for evaluation. While the serious illnesses that have been selected for evaluation are appropriate, only a handful of patients have been selected with these diseases and they may not accurately represent the illness experience of everyone with these diseases. However, these cases were chosen because they are published in the literature and for the most part are first person accounts describing their illness and are either known by many in the medical establishment or the lay public.

In summary, the purpose of this study is to establish the importance of one's changing personal identity to the experience of suffering in serious illness. It is a phenomenological analysis and utilizes narrative obtained from four different paradigm cases involving serious illness.

## **LITERATURE REVIEW**

## SUFFERING

### Overview and Introduction

Traditional medicine for several centuries has focused on a biologic model of disease in which different parts of the body malfunction. Its goal is to identify the biologic cause of this malfunction, which could be of an infectious or inflammatory or congenital or constitutional nature. The appropriate treatment would be directed at the cause of the bodily malfunction. This model has achieved outstanding success by using technology to further refine the different causes and mechanisms of disease.

Medicine, by focusing both on the body and medical technology isolates the patient. It doesn't address how a disease changes a patient's world. Each disease presents differently in different individuals and may result in different *illness experiences*. Medicine doesn't do a very good job at recognizing the patient's response to the disease (which is the definition of illness). Western Medicine doesn't always embrace the important emotional issues associated with disease. Some of these issues relate to questions of meaning and identity for the patient. As a result, the various illness meanings for a patient may go unrecognized by a physician. If these are not recognized, an opportunity to diagnose and treat the suffering patient may be lost. Thus, it is essential to determine, "how specific illness has ruptured emotional attachment with the world." (Mazis, 2001, p.201)

Eric Cassell, a psychiatrist at Cornell, has spent much of his life writing about the suffering experience. He has acknowledged that the recognition and treatment of

suffering is the paramount issue for physicians caring for dying patients. He noted that physicians are adept at recognizing objective parameters of disease in patients, but are not as skillful in evaluating the subjective element of illness. He pointed out that one must have a high index of suspicion about the presence of suffering and must ask the patient if they are suffering to really find out about its existence. He suggested that a physician must realize that the truth-value of any patient information is *not cast in stone* and is probabilistic and thus it must be used in a positive predictive way to understand better the nature of the patient. The physician must suspend all bias, not pre-judge the patient, and develop a sense of empathic communication. (1999, p. 534)

Shakespeare in his wisdom recognized suffering and spoke about the illness experience through MacBeth in his description of his ailing wife:

Pluck from the memory a rooted sorrow,  
Raze out the written troubles of the brain  
And with some sweet oblivious antidote  
Cleanse the stuff'd bosom of that perilous stuff  
Which weighs upon the heart? (MacBeth)

The emotional aspects of illness are not separate from the bodily aspects. How one perceives pain and how one is disabled by an illness may influence and change one's personal identity, as will be shown later in this paper.

The sources of suffering may be physical, psychological, social or spiritual in nature. Recognizing and treating spiritual suffering has become an important goal for medicine in the 21<sup>st</sup> century, especially in the field of palliative care. The meaning of **spirituality** goes beyond that of religion and encompasses cognitive, experiential, and behavioral aspects. It includes such ideas as a search for a purpose or truth in living and may involve such emotions as hope, love, inner comfort, and support. During the course of serious illness spiritual distress may occur when the patient is unable to find meaning in the illness experience. Signs of spiritual distress (Lam, 2003, p.3) may include:

1. expressing lack of support from others, feeling isolated, expressing guilt and expressing anger with self and others;
2. expressing no reason to live, questioning the meaning of life;
3. suppressing of feelings, being withdrawn and failing to wonder or ask questions, hopelessness, helplessness.

When the spiritual distress becomes more severe it may result in physical suffering.

Arthur Kleinman, a medical anthropologist from Harvard University, has written extensively about contextual elements of medical suffering. In *The Illness Narratives* (1988) he wrote about the stigma and shame of illness. He noted that the word *stigma* comes from the Greek “to mark or brand” and was used in ancient times to designate a person who was deformed or disgraced. This person was often ostracized and Kleinman gave as an example one with leprosy. He remarked that the

stigma of illness is present today and can be seen in one with mental illness, AIDS, epilepsy, cerebral palsy and many other diseases. He also noted that not just a disease will stigmatize but a deviation from the normal in one's body can do the same. He gave as examples a colostomy or a port wine stain of the skin. He commented that one's self is ultimately affected in these circumstances and one might feel degraded and inferior as a result.

Warren Reich has written about the moral aspects of suffering and a way of developing a model of compassion (1989). He described (p.85) suffering in the following eloquent way:

An anguish which we experience on one level as a threat to our composure, our integrity, and the fulfillment of our intentions but at a deeper level as a frustration to the concrete meaning that we have found in our personal existence.

He went on to point out that it is the meaning of the *self* that is of most importance in understanding the nature of suffering. He discussed the mental agony of suffering which he described as “the fear of obliteration of one's self through the death that will inexorably follow from one's fatal disease.”

Reich described the three phases of suffering demonstrated by one with a terminal disease. Phase one is *mute suffering* whereby a patient has difficulty recognizing, describing and communicating one's feelings. At this point one is either apathetic or feels that change cannot occur. Phase two is described as *expressive*

*suffering* in which the patient begins to develop a language that will deliver one from the suffering experience. In Phase three one develops solidarity with others who share compassion with the patient and in turn the patient develops a new voice that reformulates one's suffering experience and gives meaning to it.

Reich further wrote that one might develop several types of expression that may be crucial in recovery: the lament or the narrative. The lament just gives expression to one's suffering while in the narrative, one actually deconstructs the suffering experience and puts distance to it while becoming transformed by way of a story. The story is important in becoming a new *self* who will emerge with a new identity. The patient must find a language that describes and aids in the interpretation of the suffering experience, with metaphor being one type of language that is helpful. One may describe one's self as a **victim** or **victor** or as **condemned** or **redeemed**. As a result one makes a decision no longer to feel anguish.

The preceding discussion presents an overview of suffering in its various guises. What follows is a more concrete discussion of suffering as it occurs in several serious medical illnesses.

### Suffering and Medical Illness

This thesis is concerned with suffering in four different serious medical illnesses: AIDS, cancer, ALS, and multiple sclerosis (MS). Each of these diseases frequently results in pain and major disability before eventually leading to death.

Patients may experience significant suffering with these diseases and suicidal ideation is not uncommon. What follows is a review of some of the current literature related to suffering with these diseases and the relation of suffering to suicidal ideation.

The psychiatric literature on suicide in the adult with a serious medical illness focuses on depression and hopelessness. Kay Redfield Jamison, a well-known psychiatrist at John's Hopkins University, is an acknowledged expert on suicide. In her book *Night Falls Fast* (1999) she reviewed the various causes of suicide and relates them to mental illness alone or medical illness complicated by mental illness. The risk of suicide is highest in those with a previous suicide attempt but depression is second on the list associated with suicide. Medical illness is eighth as a risk factor for suicide. In AIDS there is a seven fold increase in suicide than expected in the population and in cancer there is a two fold increase in the risk of suicide. Many more suicides are linked to psychiatric illness than medical illness. Jamison stated, "Almost everyone who has a physical illness and subsequently commits suicide also has a psychiatric illness"(p.103). The most common psychiatric diagnosis associated with suicide in medical illness is depression. She further stated that most medical conditions in which there is an increase in the suicide risk are associated with illnesses that affect the brain and nervous system.

Suicide and suicide ideation have been studied in general medical illness and especially in AIDS and cancer. Statistically it has been difficult to sort out how much a role depression and alcohol play in suicide and medical illness. Druss and Pincus,

both psychiatrists, looked at this issue in a study from the *Archives of Internal Medicine* (2000). They studied 7589 individuals from 1988 to 1994 about suicidal ideation and suicide attempts and looked at their association with a variety of general medical illnesses and alcohol use and depression. While they found a correlation between both suicidal ideation and suicidal attempts associated with medical illness, those with two or more medical illnesses had an even higher rate yet. They used a model to control for alcohol use and depression and still found a high rate, especially in those with asthma and cancer. They concluded that most individuals who are suicidal do not meet criteria for major depression. They suggested that it might not be the illness that is related to the suicidal events but that functional disability or pain or loss of social support may be the significant triggers.

Breitbart and colleagues (1996) reported on the results of a survey of 378 HIV-infected patients about attitudes towards PAS. 63% favored policies supporting PAS, while 55% had considered PAS as a possible option for themselves. These rates were similar to those in the general population. Physical factors such as pain were not predictive of a desire for PAS, but psychosocial factors such as depression and hopelessness were. Other factors that had a high predictive value for PAS included having a family member with a terminal illness, Caucasian race, infrequent attendance at religious services, and the perception of lack of social support.

AIDS has been a baffling disease to treat and has had a devastatingly high mortality since its emergence in the 1980s. However, with the introduction of highly

active antiretroviral therapy (HAART) AIDS mortality has dropped and has converted the disease into one that is more manageable though chronic with fluctuating symptoms. Palliation of these symptoms presents a challenge for the physician, since AIDS patients frequently change their mind about treatment and advanced care options as their symptoms wax and wane.

Selwyn and Forstein reported on new treatment paradigms for treating these patients (2003) and have argued against using a curative vs. palliative strategy for treatment, but have suggested that one can both palliate symptoms and attend to curative strategies concurrently. They stressed that physicians should be both flexible and tolerant in their approach to treating AIDS patients and should frequently address their patient's concerns about advanced care. They described a patient with a long history of AIDS and his ambivalence about continued living with the disease and the associated aggressive treatment versus cessation of all medical care. I will be using this case later to examine the issue of changing personal identity in the face of a serious chronic illness.

It is commonly thought that cancer patients experience suffering in the advanced stages of their disease. Cherny et al have provided an excellent review of this topic in *The Journal of Palliative Care* (1994). They have noted that unless suffering is acknowledged and treated, the value of life for the suffering patient is undermined. They have provided both a definition (p.57) of suffering and taxonomy of those salient features that contribute to suffering. Their definition of suffering:

1. One must have sentience or the capability of perception by the senses
2. Those factors that undermine life must be distressing
3. The experience is aversive with a sense of helplessness or loss.

There are physical, psychological and existential factors that may be responsible for distress in the advanced cancer patient. Physical symptoms are present in the majority of these patients and include pain, fatigue, weakness, and shortness of breath, confusion, and vomiting. These symptoms interfere with the patient on many levels and may disrupt eating and thinking and sleeping and social interaction.

Psychological symptoms occur in 60% of patients with advanced cancer and include adjustment disorder, depression, anxiety, and delirium. In addition those physical factors of pain and disability may cause feelings of loss and hopelessness and contribute to suicidal ideation.

Existential distress, a condition not frequently recognized by physicians, may include hopelessness, futility, death anxiety, and disruption of one's personal identity. This distress may interfere with one's concept of personal identity as it relates to past, present, or future events. One's bodily identity or body image may be disrupted by an advanced illness and the consequences may spill over into one's perceived attractiveness or one's ability to function sexually. Advanced cancer may also impede one's functioning professionally, socially or intellectually. As a consequence of these changes in one's *self*, a person may in retrospect become despondent concerning the worth of previous achievements.

The authors have pointed out how this great disappointment in life can have dire consequences (p.59):

If life is perceived to offer, at best, comfort in the setting of fading potency, or at worst, ongoing physical and emotional distress as days pass slowly until death, anticipation of the future may be associated with feelings of hopelessness, futility, meaninglessness such that the patient sees no value in continuing to live.

They have pointed out that this existential distress occurs to most patients and only a few patients accept their death without anxiety.

The authors have described the mutual interplay of distress and suffering that occurs between patients and their personal caregivers and their physicians. The patient may develop empathic distress and feelings of nihilism upon perceiving anguish among family, friends, and healthcare providers. The psychosocial stresses among family and friends are many and include: observing the impending death of a loved one and deciding how to live the final days with them, financial issues, and psychological issues related to the burden of being a caregiver. These caregiver burdens include hygiene, laundry, sleep deprivation, and physical work. It is not rare for a caregiver to temporarily leave their job to care for the patient and this may have an impact on their income. Thus, there may arise conflict about a caregiver deciding whether their responsibility is primarily to themselves or the patient.

The healthcare professional in many studies may report burnout from the demands on them as doctors to these very sick patients. The impact may spill over into their personal life or social life. Cherney et al have observed that the healthcare provider has as a goal to prolong survival, optimize comfort, and optimize patient function. Unless, however, health providers become aware of these issues which relate to the suffering of patients, personal caregivers, and themselves they will not be able to meet the goals of care.

Breitbart & colleagues (JAMA, 2000, pp. 2907-2911) conducted a survey of terminally ill cancer patients at a palliative care hospital in New York City. The survey gathered information about their desire for hastened death and was conducted between June 1, 1998 and January 31, 1999. Of ninety-two patients surveyed, 17% had a significant desire for hastened death and of these patients, those that were depressed were 4 times more likely to desire death than those who were not depressed. Feelings of hopelessness were independently associated with a desire for hastened death. Other variables associated with a desire for hastened death include issues related to spirituality, quality of life, one's physical functioning and "a perception of being a burden to others." No association was found between pain and the intensity of pain and a desire for hastened death although they do make the disclaimer that pain control at this palliative care hospital was excellent.

Amyotrophic lateral sclerosis (ALS) is an inexorable disease that leads to progressive paralysis. Late in the disease patients lose the ability to talk, or write, or

eat and become completely dependent on others. Most patients die within 5 years of the diagnosis and prior to death frequently develop respiratory paralysis for which they have to make a decision about having a tracheotomy and being placed on a respirator. This disease may lead to suffering and suicidal ideation.

Ganzini, Johnston, McFarland, Tolle, and Lee wrote an article in *The New England Journal of Medicine* (1998) concerning the attitudes of patients with ALS and their caregivers about PAS. They surveyed 100 patients with the disease between 1995-1997 in Oregon and Washington. The mean age was 54 and the duration of the illness averaged 2.8 years. Fifty-six percent of the patients would consider PAS. These patients were more likely to be married white men who were less religious, who had higher scores for hopelessness and who rated the quality of their life lower. Seventy-three percent of the time caregivers of these patients shared their attitude about PAS. The study showed equal amounts of depression in the group who would participate in PAS and the group who would not. Scores on hopelessness were higher in the group who would commit PAS. This article suggests that there is increased existential distress or suffering in a majority of patients with ALS, which would lead them to participate in PAS.

In an accompanying editorial by Rowland, it was pointed out that 10 percent of these patients are under 40 years old and 10 percent develop “locked in” syndrome whereby the patients are totally paralyzed but have full cognition and can only communicate by eye movements. He noted that there is increased hopelessness but

not suffering between the two groups, which raises the question how one can feel hopeless and not be suffering. He also described the dilemma facing physicians who usually must give full disclosure to patients about the disease, but by doing so would almost certainly cause a loss of hope for them. He stated that most physicians focused on treating symptoms and looking for new treatments.

Rowland also pointed out that while many of these patients may desire PAS, by the time their disease had sufficiently progressed, the patients were too weak and could not give themselves an overdose of the medicine. They would then either have to take an overdose at an earlier stage of the disease or enlist a physician, family or friends to help them. However, the giving of an overdose of medicine in this manner would either be considered euthanasia or murder and is illegal in this country. Thus, ALS presents as a bad disease with the potential for much suffering and moral quandary.

### Alienation

Alienation may also lead to suffering and suicidal ideation. An ill person develops an awareness that the body is not functioning as it should. One feels alienated from one's normal healthy *self*. In a similar manner there may be external causes of alienation that disrupts one's normal *self*. Many observers have written about the alienating effects of medical technology in the 20<sup>th</sup> century.

Arthur Frank in writing about his treatment for testicular cancer in *At the Will of the Body* (1991) stated that surgery and chemotherapy “disrupted one’s continuity with the past”(p.38). He noted that the challenge of chemotherapy is learning how to live when one’s life has been so radically altered by the treatment. Anatole Broyard in writing about his prostate cancer stated in *Intoxicated by my Illness* (1992) that one had to struggle against the dehumanizing pressure of biomedicine. These descriptions clearly indicate how the treatment for an illness can be alienating.

David Morris wrote about the effect of living in a postmodern world on one’s perception of illness in *Illness and Culture* (1998). He asserted that, “people fear hospitals and doctors more than they fear dying”(p.28). In suggesting that patients may feel alienated by their doctor he quoted Sherwin Nuland: “When faced by the certainty of his own impotence to treat it, the would be healer too often turns away.”(p.16) Morris then articulated the frequently suggested idea that the biomedical model of medicine has failed. He speculated that by doctors abandoning their patients in their illness, all that is left is physician-assisted suicide (PAS).

### **PERSONAL IDENTITY**

Are we just bodies? Is our mind part of our body or separate from it? Is our body responsible for our thoughts? Do we actually exist or is our existence just conjured up as an idea in someone’s mind? When we look critically at the notion of personal identity it is apparent that the ramifications of this concept can be extended

to areas outside of philosophy. It is important in the law when people are considered as moral agents. It is important in religion when people debate whether we *survive* despite the death of our body. It is of course important in medicine and in the debates about death and dying.

The concept of personal identity is critical to understanding the psychological changes that one undergoes during a critical illness. In health as well as in illness we have the tendency to identify ourselves with our bodies. As Richard Taylor has so nicely stated in *Metaphysics* (1992), “One has a solicitude for his body wholly incommensurate with his concern for any treasure, however dear”(p.15). While there have been many attempts over the centuries to define personal identity, none of them meets with universal acceptance. There are however, some concepts basic to all efforts to define it as philosophers and psychologists try to determine what makes you who you are and not someone else. What attributes do you have that make you unique?

Questions arise about what evidence needs to be collected to demonstrate that the person you once were or will be is the same person that you are now, a concept called *persistence*. Thus, in answering these questions one collects information from memory or from looking at bodily continuity, as can be found in photographs. One tries to establish if there is one of you at a given time, *synchronic identity*, as opposed to *diachronic identity*, which is one’s persistence over time. From these concepts arise other important terms including *numeric identity*, which is defined as being one and

the same person over time, and *qualitative identity*, which relates to the presence of two people equal in every way, such as identical twins. There also continues to be ongoing debate about the importance of the body to establish identity versus the importance of psychological continuity as the key to identity.

### **Theories of Psychological Continuity and Personal Identity**

French philosopher Rene Descartes (1596-1660) asked ‘What am I?’ and introduced the idea of identifying one’s self with the soul. He was interested in the continuity of the mind or soul over time, which suggested an early interest in the idea of personal identity. Descartes, however, did not develop his ideas in this area to the extent to which did John Locke (1632-1704). It was English philosopher Locke who expanded the concept of identity over time and identified other important ideas that have become central to the debate on personal identity. In his ‘Of Identity and Diversity’ found in *An Essay Concerning Human Understanding* (1694), Locke gave his definition of a person as:

A thinking intelligent human being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places (Great Books, vol.33, chapter 27, 1993).

Locke reflected on the possible meaning of personal identity by a thought experiment in which the soul of a cobbler enters a prince and the soul of a prince

enters a cobbler (2.XXV11.15). He said that the soul carries our consciousness and as a result the person of the prince is in the cobbler and vice versa. He further stated that a person has reason and self-reflection of past actions that occurs through the senses of smell, taste, and feel.

His theory of personal identity was useful as part of his overall view of life and its rewards and punishments. The same consciousness must own that person's previous actions. Thus, one cannot claim he was not the same person who committed a previous crime, but must be responsible for his actions, a forensic theory that is still useful in legal circles today. He also said that when one met his *maker* at the end of life, that his reward or punishment again related to his previous actions over a lifetime. However, one of the weaknesses of this idea relates to one only being responsible for what one remembers.

David Hume wrote that we are not always aware of every perception as being related to oneself. He described the *self* as a bundle or aggregate of perceptions. It was Hume's idea that every perception stands separately and that one could not unify these perceptions into a single continuum over time, as a theory of personal identity would require. Thus, he believed that one could not satisfactorily develop a theory of personal identity.

There is some debate as to whether the issues related to personal identity are the same as those of continuing identity. In both, however, there is discussion of the importance of the biologic aspects versus the psychological aspects of identity. A

variety of thought experiments, many of which are purely theoretical and could not actually occur, are used to emphasize key aspects of this ongoing debate.

Derek Parfit (1971) held that personal identity consists of psychological continuity. He described elaborate thought experiments involving transplanted and transected brains. He saw personal identity as important in understanding questions about survival, memory, and responsibility.

English philosopher Peter Unger is a strong proponent of a theory of psychological continuity as a basis for determining personal identity. In his article *Survival of the Sentient* (2000) he laid a foundation for his theory. He started with a definition of a person as one who extends through time and occupies space and thus has persistence. This person has egocentric values and is physically complex. Unger applied this theory to sentient beings (humans) and nonpersonal sentient beings (animals). He employed a variety of tests of personal identity and contrasted those with Eric Olson who advocated a biologic approach to the problem of continuing personal identity.

Unger used the **Avoidance of Great Pain Test** to argue that if your brain were transplanted into another body, you would prefer to have pain inflicted on the body from which the brain was removed rather than on the body to which the brain has been transplanted. This suggested to him that the real person is that one who has his original brain transplanted into a new body. Unger also said that any theory of personal identity has to be compatible with our morality.

In another thought problem Unger described two identical twins that have the exact appearance but different brains, each with a different psychology. He stated that if one twin mentally ceases to exist, the twin ceases to exist even if the body remains. He stated that if the mind no longer exists then the sentient being no longer exists. In a similar way he described the **Brain Explosion Case** in which a canine brain is in a vat with its body being kept alive on a life-support system. He stated that if the canine brain explodes, the sentient being no longer exists. He used these tests to support his argument about psychological continuity as necessary for personal identity as opposed to biologic continuity (the presence of a body). Unger did place a stipulation that biologic continuity is important if its presence is important for the continued existence of one's mind.

Unger ventured into other interesting areas concerning personal identity and discussed the implications of existing without a mind or other psychological support. He described Trudy the tree and Sylvia the skin cell, both of which are alive. However even if they die they still exist which suggests that being alive is not essential for their existence.

To summarize Peter Unger's views one would state for continuing identity to be one's own, a person must be sentient and persist in time and space. One must have egocentric values as well as a morality such that one would want to avoid pain or suffering such as one might experience in a variety of thought experiments. A sentient being with these values continues to exist even if one's brain is transplanted into

another body, since the presence of one's own body is not essential for psychological continuity. Thus, a person exists only if one's mind exists.

Galen Strawson outlined (1997) a theory of personal identity that is currently popular in philosophy. He noted that we all have a sense of our *self* though we don't really understand it. He stated that we first are aware of our selves as a mental thing in childhood, especially when we are alone and thinking. He described this mental self (p.408) to have the following characteristics:

1. A thing in some robust sense
2. A mental thing
3. A single thing that is synchronic and diachronic
4. Ontically distinct
5. A subject of experience, a conscious feeler and thinker
6. An agent
7. A thing that has a certain character or personality.

He proceeded to explain that he is a materialist, which he describes as one who believes that everything in the universe is physical in nature. As a result his theory describes a type of mental materialism that is associated with the physical. He first described the *self* as a mental *self*, which is a thing that can do things. He

described it as being singular in that it has unity. It is single synchronically in that it exists at a given time and it is single diachronically in that it persists over time. He stated that the self doesn't have to be aware of itself as a personality.

He portrayed people as either living in a narrative mode in which they develop projects and plan for the future or live their life without a narrative and either live intensely in the present or live aimlessly. He said that the *self* doesn't have to have a sense of some long-term continuity. He tried to give a sense of the *self* in time as being almost like a stream of consciousness in which our thought patterns are very uneven and our train of thought is interrupted. He stated that we may go long periods of time without thinking about ourselves but then we may have sudden unsuspected introspection.

Strawson illustrated his concept of the *self* by drawing an analogy to pearls on a string. Each pearl represents a separate mental self which he described as, "any uninterrupted or hiatus-free period of consciousness...which exists for a short period of time but is as real as a rabbit"(p.425) He said that the *self* is ontically distinct and as a materialist believed that it results from a state of activation of neurons by a neurotransmitter. His psychological theory of personal identity can be contrasted to those theories of bodily identity, which will be next discussed.

### **Theories of Bodily Identity as essential for Personal Identity**

The debate throughout much of the 20<sup>th</sup> century has gone back and forth between the importance of bodily integrity (biologic model) versus psychological continuity for maintaining one's personal identity. One of Wittgenstein's contributions to this area includes the idea that to observe an inner process one needs outward criteria. For this reason there was a need for observable criteria for the identification of psychological processes and this led to an increased interest in bodily identity as a criterion for personal identity. Thus, to develop criteria for the identity of one's self, a first person approach was adopted, but to identify someone else, a third person approach was developed which relied on the identity of a body.

Oxford philosopher Bernard Williams wrote a series of papers on this topic (1956/7, 1973) and concluded that bodily identity is necessary but not sufficient for personal identity. He said that memory played an important role. Williams further stated that a way should be developed to determine the exact body and the exact memory that would establish one's identity compared to someone else's identity.

A.J. Ayer stated that a person only becomes aware that his consciousness is his own if he can identify with his bodily experiences (1963). One then must see a causal relationship between mental and physical events. This concept becomes important later in the phenomenological analysis of pain and its relation to one's personal identity.

Eric Olson is a materialist philosopher who believed that psychology is irrelevant to our persistence. He believed that biologic continuity is the determining

factor in one's identity. In his book *The Human Animal* (1997) he used thought experiments such as describing a patient on a respirator who has lost his higher cognitive abilities and is in a persistent vegetative state. He maintained that his patient retains an identity because of the presence of life-sustaining bodily functions. He rejected the brain transplant arguments such as those given by Parfit, since one's personal identity remains with the body, not the transplanted brain.

This review of personal identity is essential to understanding the argument presented later in this thesis on the relation between chronic serious illness and changing diachronic identity. With the progression of illness one's bodily identity changes and this may change one's psychological identity. Independently of one's changing bodily identity, a chronic illness, through disembodiment and alienation, can change one's psychological identity. One's reaction to these changes in identity over time is to change one's personal narrative, and this may result in suffering.

### **NARRATIVE: TELLING STORIES AND ILLNESS**

An appreciation of the function of narrative is critical to make sense of illness and the *self*. Narrative or story telling is important not just in medicine but also in such fields as philosophy and psychology. As humans we try to make sense of our lived

experience by telling stories. Howard Brody in *Stories of Sickness* (2003) quoted Mark Johnson as stating, “every one of us is actively plotting our lives, both consciously and unconsciously, by attempting to construct ourselves as significant characters within what we regard as meaningful life stories.”(p.25) When something bad happens to us we turn it into a story that we can understand.

Our lives have a history and a temporal framework. We use metaphor as a narrative tool to present our story to a community with which we share a common culture. We invite the listener into our narrative. The narrator and the listener share a complex interaction in a search for meaning. Psychologist Jerome Bruner (1986) recounted how listeners must construct meaning of a story based on their own experience. He noted how a story changes in content every time it is told and retold. The language used by the narrator may mean one thing to that person and another to the listener. Thus, our minds supply coherence to a story but one can't know for sure what the narrator was thinking.

It will become apparent in the course of this thesis how narrative helps one sort out issues involving the *self* in critical illness. Rita Charon (2002) noted, “the self is inscribed in its stories”(p.61). She further stated, “we learn who we are backwards and forwards, early memories taking on sense only in the light of later occurrences and contemporary situations only in the web of time”(p.61). The *self* only has meaning in the context of its relationship with others. It is this constant interaction with other people that allows the *self* to make choices and which adds a moral

dimension to the narrative. These moral issues in the course of illness will also involve the caregiver and those who have a relationship with the patient.

One can understand the role of narrative in illness better by analyzing the effect of illness, especially critical illness, on one's outlook after becoming ill. It is common to develop a victim mentality when becoming seriously ill. It is easy to feel sorry for one's self, but the consequences include anger and detachment from others. This increasing isolation can lead to increasing physical pain and mental pain or anguish. According to Arthur Frank in *At the Will of the Body* (1991), "critical illness takes its traveler to the margin of human experience"(p.54). One may lose their identity and develop doubts about the future.

Narrative allows the opportunity for those who are critically ill to share their misgivings with others. It brings the hope of establishing new positive relationships with others. Putting fears into words allows patients to situate themselves in their life. As David Morris (1998) so nicely stated, "When people tell stories they see the meaning of life, the path they have taken, and approach the event of their death very differently"(p.251). Narrative gives one the opportunity to fulfill obligations and to set goals and can open up communication between themselves and their loved ones and their caregivers.

One of the tools used in narrative is metaphor. When one is ill and begins to tell a story it allows one to compare that person's story to others. It allows the development of a moral dimension, which will give additional meaning to the illness.

Brody pointed out the complexities of narrative in his recent book *Stories of Sickness* (2003). He noted that initially patients, based on their own experience, construct a personal meaning out of their illness. However, every time the story is repeated it takes on a different meaning for both the patient and the listener. He emphasized that every story takes place in the context of its own culture.

Brody pointed out (p.30) that there are 4 levels of narrative in healthcare:

1. Patient's stories about their own illness
2. Patient's life story within which their illness episode occurred.
3. Patient's life story fits into the general stories that make sense in our culture.
4. Patient's story and its transcendental narrative-situating it into the *larger cosmos*.

Thus, there is no one meaning of an illness narrative but a different meaning on each level.

Narrative plays an important role not just for the patient but also for the physician who interacts with the patient. Traditionally physicians use reasoning and perform habitual actions in their treatment protocol. When ethical conflict arises in the care of a patient, a physician will resort to a juridical approach, looking for such

universal principles as autonomy, beneficence, non-maleficence, or justice for resolution. However, many of these conflicts are emotive and not objective and are not readily amenable to this traditional method of conflict resolution.

There is an alternative way of dealing with these problems by appealing to contemporary literary theory. Charon and Montello in *Stories Matter* (2002) hold that the actions of patients can be divided into external and internal ones. The internal actions can best be described as the way one thinks or philosophizes and are under moral accountability. It is the role of the physician by using narrative encounter to make “moral behavior intelligible and to negotiate differences and disagreements”(Brody, p.177). The physician thus is using narrative to apply moral principles in the context of a particular illness. This is a much more satisfactory and personal way of solving bioethical conflict.

Charon has further elaborated on the value of narrative in medicine in a recent article published in the *New England Journal of Medicine* (2004). She noted. “Only in the telling is the suffering made evident”(p.862). Charon referenced several books in which the use of narrative has proven value to allow physicians to better understand and connect with their patients and to understand their own lives as healers. Among these novels are included: *The Diving Bell and the Butterfly*, *Seeing the Crab*, and *Touching the Rock*. These narratives allow one insight into “transcendental truths” that may not otherwise be revealed. An additional benefit of

using narrative in medicine, according to Charon, is that patients have their self-worth confirmed when their story is listened to by the empathic physician.

Thus, the narrative approach to ethical conflict that arises in critical illness joins the healer with the patient. The physician will have an emotional response which will lead to moral decision making in a way that standard bioethics can't do. The moral life of the physician and the patient are enriched as a result.

I have presented selected literature on the general theme of how critical illness may change one's personal identity. It demonstrates the importance of narrative in understanding illness and the *self*. It also touches briefly on issues related to suicide and serious illness. Lastly, it provides a backdrop for my observation that the alienation or disembodiment that occurs in serious illness is caused by one's change in bodily and psychological identity as the illness progresses. It is this changing identity that is crucial to the development of suffering.

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### **BIOETHICS RESOURCES**

1. <http://bioethics.od.nih.gov/general.html>----National Institute of Health web site—with nice resources
2. <http://www.bioethics.upenn.edu/> ----Good site for general bioethics
3. <http://bioethics.Georgetown.edu/>----Kennedy Center of Bioethics at Georgetown University. Access to extensive literature on bioethics
4. <http://litmed.med.nyu.edu/Main?action=new>---- Literature, Arts, and Medicine database from NYU
5. <http://www.lib.ncsu.edu/guides/bioethics/references.html>----Nice site for journal articles, reference books and other web sites
6. <http://healthlinks.washington.edu/clinical/ethics>----excellent resource web site

### **PHILOSOPHY RESOURCES**

1. [http://philosophy.gmu.edu/Philosophy\\_resources.htm](http://philosophy.gmu.edu/Philosophy_resources.htm)—excellent resource for general philosophy

