

1998

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Dealing with Death and the Grieving Process

Presidential Scholar Senior Thesis

University of Northern Iowa

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Spring 1998

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Faculty Thesis Advisor Date

4/15/98

Janet M. Rives

Chair, Presidential Scholars Date

May 7, 1998

There are two things that our society doesn't really openly discuss. Oddly enough, they are things that will affect everyone on this planet regardless of race, religion, gender, class, or nationality. I am speaking of the beginning of life, and the end of life. The subject of how life begins is for some reason "taboo" in our society. Children are told absurd things like children are brought to their parents by birds, such as a stork. Another popular tale is that children are "grown" in gardens and are discovered under leaves. The subject of sex seems to be one that we deem unsuitable for discussion under anything but the most "special" circumstances. As a result, there are a lot of misconceptions and harmful myths surrounding how life begins. I have found that stigmas also surround what this paper will concentrate on, the topic of death, often times having harmful results as well.

Although death is something that will affect everyone, we tend to treat it as another unspeakable topic. Children are once again told shrouded fallacies such as that someone who has died is away on a trip, or that they are just sleeping. Perhaps such tales are told with good intentions, but they do nothing but serve to make the topic of death even more mysterious and frightening. I remember as a child thinking that dying must be a terrible thing because nobody would talk to me about it. While death is not a pleasant thing, it is indeed a natural process.

Elisabeth Kubler Ross writes in her book, On Death and Dying, about how death was dealt with while growing up in Europe. She recalled a farmer falling out of a tree and being fatally wounded. He asked to die at home, and this request was granted without question. This could hardly be said about our society. He requested to speak to each of his daughters for moment alone, settled his affairs, and bid his friends goodbye. Kubler Ross states that she was a small child at the time, yet she was allowed to share in the experience. She was aware of the preparations leading up to the farmer's death, was in the home when he died, and was also included in the grieving that followed. Even today in her homeland, the dead are not embalmed. No make-up is applied to give the appearance that the dead are only sleeping. The reality that the person has died is not denied. Kubler Ross feels that such practices are an acceptance of a fatal, but natural outcome, and I agree fully.

I have come to know that life is a very difficult journey. There have already been times in my short life that have been so difficult, that I would not have been able to make it through them without the help of my family and friends. Dealing with impending death must for some be the most frightening and trying experience possible. It is at this time that they need the support of their family and friends most. However, so often that help and support is not there, and the patient is left alone and isolated, at least in spirit if not in presence. Many times, the friends and family of the patient deny the "fatal outcome." They refuse to accept the fact that the patient is going to die. They therefore cannot help the patient prepare for what is truly inevitable. Moreover,

the fear of dying that the friends and family may have will more than likely be visible, serving to increase the fear and anxiety of the patient.

Kubler Ross states that, "Dying becomes lonely and impersonal because the patient is taken out of his familiar environment and rushed to an emergency room...When a patient is severely ill, he is often treated like a person with no right to an opinion." In our "modern" medical system, we pride ourselves on being able to prolong life as long as possible. The question which we are now beginning to face is whether or not we should do something just because we can. We may be able to keep a terminally ill cancer patient alive an extra three months by giving them painful and weakening radiation treatments. However, with or without the radiation, the patient is going to die within a very small span of time. Is it the "duty" of the health care providers to do everything they can to give every patient every last second of life possible? In the opinion of this student, the answer is no. Truly "living" goes beyond mere "biological life". I do not feel that a person who experiences nothing but constant pain and suffering is really living, even if their bodies continue to function. The body can in some cases be a prison of one's mind and consciousness.

My reasoning for this answer is twofold. I believe that among other things, it disrupts the grieving process for the terminally ill patient. I also believe that equally as important, the grieving process for the family and friends of the patient is disrupted. Kubler Ross breaks the process of dying into five stages. The first of these stages is Denial and Isolation. When a patient is first told that they have a terminal illness, their first reaction is usually to say that it cannot be true. They

refuse to believe that they are sick, and they often go from doctor to doctor trying to get a more positive second opinion. It is important to allow the patient this period. According to Kubler Ross, denial and isolation allow the patient time to adjust to the profound realization that their life is drawing to a close. There are many people who realize one day that, "There are fewer days ahead than there are behind." But to actually be told that you have a very short amount of time left to live is a harder hitting fact to face. Kubler Ross feels that it is important to realize that just because a patient is in denial, that they will not necessarily never want to talk about their condition.

It has been my experience that if a patient is going to attempt to come out of isolation and talk with someone, it would most likely be with a close friend or relative. If you take a terminally ill patient out of their home and place them in a clinical setting, you are increasing the chances that they will remain isolated. Therefore, another factor to consider is how comfortable a patient is with their surroundings. People tend to be more willing to discuss serious matters if they are at ease in their surroundings. I have seen patients talking with a health care worker in a hospital. To most, the hospital is an alien environment, one in which they feel uneasy in. I have observed a very noticeable difference in patient mood when visited by a hospice nurse in their own home. There is a big difference between having your pulse and blood pressure checked while sitting on cold bench in a doctor's office and having the same thing done while sitting in your favorite recliner in your living room. I believe that patients are more at ease and likely to talk about their illness if they are treated at home as long as

possible.

The second stage as defined by Kubler Ross is anger. After the defense mechanism of denial begins to give way to reality, the patient often begins to feel anger and rage, often times directed at nobody in particular. Anger is a much more difficult stage of the dying process for family and friends to deal with than denial and isolation. During the first phase, the patient often continues along in life as if nothing has changed. Those around them are able to maintain their usual routine and ignore the situation as well. They often feel that if the patient is not worried out it, why should they be. At the very least they do not feel that they should force the patient to face this reality, and that they must accept it themselves at their own pace.

Once anger sets in, all of that changes. All of the anger and rage that the patient is feeling is often randomly directed at anyone around. A major problem that Kubler Ross examines is that most people don't put themselves in the place of the patient and fail to realize just where all their anger is coming from. Perhaps they too would feel anger and rage if their lives were being brought to a halt, and they were forced to accept that many of their life ambitions would go unrealized.

This is a stage where understanding the patient's feelings is crucial. A man who has been very independent and in control all his life is likely to act out in anger toward his caregivers when faced with a debilitating illness. The acts of kindness performed by caregivers serves to remind the patient of his "weakness". They remind him of all the things that he is no longer able to do.

This is what Kubler Ross calls “rational anger.” It can be dealt with if the people who deal with the patient attempt to put themselves in the patient’s place and understand his or her feelings. In the case of one man in the book, the nurses began to ask what times would be best for him to have certain tasks performed. These would include infusions, or the changing of his sheets. By doing this, he was given back some of the sense of control he needed, and his anger subsided. In this case, all that needed to be done was to communicate with the patient. This seems simple enough, but because the patient was “dying”, the caregivers did not know, or felt uncomfortable talking with this patient.

At this stage, I am not sure if I feel that in-home care would be a great advantage. Family members are not immune to the “rational anger” of a terminally ill patient. I feel that a person can often be more angry at a family member who is caring for them because of guilt. In a clinical setting, it is the job of caregivers to attend to a patient. Not many people feel terribly guilty about being a burden to doctors and nurses, especially not when they are footing a large bill. However, when the primary caregiver becomes a child, parent, or spouse, the patient can begin to feel guilty about the sacrifices that are being made to care for them. Sometimes, the caregiver wouldn’t have things any other way. I recall a Hospice case where one elderly sister was taking care of her sister who was also elderly. She refused any outside help and insisted on caring for her sister herself. At the time, I recall admiring that sister for the dedication, devotion, and love that she was showing. But, I have since wondered if guilt wasn’t also a motivating factor. Guilt on anyone’s part can lead to resentment.

Resentment can lead to more anger, and that can lead to loss of support. If in-home care can be administered without such problems, then I am all in favor of it. But, if it cannot, then I feel that the cons may outweigh the pros at this stage.

The third stage of the process of dying is bargaining. Patients in this stage often make deals with their god or some other supernatural power. They often ask for their life to be extended until a certain event occurs. They may ask to live to see a child graduate from high school. They may ask to live until one of their children gets married. However, many people continue to make bargain after bargain after each one is "granted." In this way they try to cheat death by keeping it one step away at all times. Bargaining is something that I have done myself, but not because I was terminally ill. Bargaining can occur due to other problems. During rough times, I usually ask God to help me through things. In "exchange", I usually promise to better myself and lead a more ideal life. There was a man who attended my church who had been to services every Sunday for decades. He had once made a bargain with God. His wife had been very ill, and he promised God that if his wife would be saved, he would attend church every Sunday, no matter what.

After bargaining comes depression. According to Kubler Ross, "anger and rage will soon be replaced with a sense of great loss." This sense of loss is something that I feel is absolutely crucial. Loss is something that we experience throughout our lives. It is something that is not restricted merely to death. We lose jobs, homes, friends, and many other things through things as commonplace as moving to a new community or graduating from school. We

tend to ignore the significance of loss and the effects that it can have on our lives. In terminal illness, patients often are experiencing the loss of their physical capabilities, perhaps even to the extent of losing the ability to take care of themselves. Along with this comes the loss of dignity and self-worth.

Finally comes the stage of acceptance. I found it interesting that in this phase, the patient gradually sleeps more and more, however, not because they are giving up the struggle against their illness. In fact, they are merely following a natural pattern, "increasing need to extend the hours of sleep very similar to that of the newborn child but in reverse order." I have heard before that humans begin life as they end it. The very old and the very young share common traits like susceptibility to illness, inability to care for themselves (for the elderly this may be due to a lapse of physical or mental capabilities), and the need for extended hours of sleep. Some patients however, never accept their condition and fight to the end. According to Kubler Ross, these are the patients who completely give up one day and utter the words, "I just cannot make it anymore."

In reading Kubler Ross, I was struck by the incredible variability in the way people cope with death. I immediately realized that this obvious fact should not have been a shock at all. Each person is an individual. They have had experiences and perceived things in a way that no other person ever has. It only stands to reason that they would cope with the end of their life in a way unique to them. Although there are similarities in the way people cope with dying, Kubler Ross said more than once in her book that she had never seen a patient cope with or deal with dying in the same way.

Hospice care addresses many of the issues examined by Kubler Ross. Hospice care recognizes that a patient and their family are faced with a wide array of choices concerning their medical care. This comes at a time when the family and patient are perhaps least capable of dealing with such decisions. Hospice care is for patients who are suffering from a terminal illness and have six months or less to live if the illness follows its usual course. I feel that the strength of the hospice movement is that the care received is decided by the patient. Hospice takes care of all aspects of patient care ranging from the clinical to the psychosocial to the spiritual. In the Hospice environment "wishes of the patient whenever attainable are paramount in decision making." This is similar to Kubler Ross's story about the farmer who was allowed to die at home. His wishes were the top priority and he died in the environment he wished. On a special note, it is important to make the distinction that Hospice "seeks neither to hasten nor postpone death." Life is merely allowed to run its natural course.

Once again I am surprised at my own arrogance. Coming into this project, I thought that I had some pretty good answers at how to help patients deal with dying. As a physician, I will obviously have to deal with dying on a frequent basis. I thought that as long as you looked at death as a natural process, that most people could be made to accept it. I once again fell victim to assuming that most other people think and reason like I do. While I have the feeling that I am not the only person to ever err in this way, I feel as though I should know better. Being a person who was always the "different" one in the room, I have always tried to be extra aware of the uniqueness of people and how

those variables would affect each person's reasoning and perspectives. But in this case, I have clearly failed up to this point.

Once again I must wonder if I will be able to "connect" with patients in a clinical setting. I have led an admittedly sheltered life. I grew up in a small town in Iowa. There were very few minorities around, and while I myself am an ethnic minority group member, I was not raised that way. Therefore I can really not claim to be all that diverse of a person myself. I wonder if I was placed in a large urban center, if I would be able to function well as a caregiver. Despite this, I choose to have faith in myself. I choose to believe that I have the ability to think new situations through, to rationalize things, and to adapt to new situations.

Before I leave the topic of death, I feel it necessary to comment on our society's value on life. I have come to think of life as a great gift. I really try to see the good in everyone and recognize how each person's uniqueness is an asset. However, I feel that our society tends to take life for granted. Recently, I watched a television program on the Los Angeles County Coroner's office. That program made it clear that there is a gross disregard for human life in our nation. People are gunned down at random. Their lives are ended without remorse or sorrow. The saddest deaths of all are perhaps those who have no family. These are the ones that lie dead in the streets for weeks because nobody misses them...nobody notices that they are gone.

I now turn to how we deal with grief. I feel however that grief due too loss through death is to narrow a spectrum to examine though. We experience loss throughout our lives. I am beginning to realize that life is more or less a series of

cycles. Life never “gets better” and stays better. I think that there are the good times, and with them the bad times. I do feel however that in the last four years I may have had a disproportionately large share of the bad times. I have had to deal with the stresses of college, clinical depression, my father’s manic depressive illness, divorce of my parents, moving to a new home, and many other changes and stresses. However I feel that it is important to keep things in perspective. Compared with some people, my life has been a fairy tale. Never have I been cold, hungry, or neglected. I have been very lucky in the grand scheme of things.

Today our lives move at a blistering pace. Our world today changes quickly, and with those changes come losses. Grief can occur from losses other than death. “All significant loss results in grief. If you’ve lost a grandparent, a pet, a job, or had to move, you have experienced loss and grief, and the associated stress.” Normally, a person can cope with stress without it disrupting their lives too severely. However, when the stress is too extreme, a person’s normal coping methods are inadequate. Dealing with grief is a cyclical process. “Half of dealing with grief is recognizing this cycling process...and working through the disruption and pain that accompanies it.”

This is something that I agree wholeheartedly with. I have had many experiences recently that have made me feel great amounts of grief. It seems that just when I am getting over one, another seems to creep up. The process of grieving and healing really seems to be cyclical. The real problems for me have occurred when I have been unable to heal from a painful experience, or when

too many problems have occurred simultaneously.

The grief process can cause incapacitation. This is something that I know about firsthand. I am more and more astonished as I research for this project, how much is documented about grief and depression, yet how little is commonly known. Reading some of this literature is like reading a book about my life. A major part of the incapacitation mentioned is a mental incapacitation. This is something which I suffered through. During my depression, I found that my mental abilities were reduced. I was unable to concentrate or remember things I had just read or been told. I also suffered from loss of appetite, sleeplessness, and personality changes. These are all textbook symptoms of depression. Since you cannot separate mind from body, there was also a physical incapacitation that accompanied the loss of mental ability. I read in the literature that extreme grief can cause a person to totally collapse because they don't have enough mental energy to deal with the stress and even maintain their sense of balance. At my worst point in my depression, it took a great deal of mental effort for me to do things such as force myself to eat. I never felt like eating, yet I knew that I had to do so. It was a chore to force a few mouthfuls of food down. It took all of the mental energy I had left to follow a basic daily routine that one normally does without even thinking.

As I look back, I realize that during this period, I knew that something was wrong, and that I was actively doing something to find a solution. I sought out different counselors, doctors, medicines, etc. This was part of my mind realizing that my current coping methods were ineffective and that something different

needed to be done.

One thing not to do at this time is say things such as, “ It could have been worse; or, You just need to work harder and take your mind off it.” Suggestions like these seemed like a slap in the face. Sure...it could have been worse. But that didn't mean that the situation I was in wasn't bad. Telling me to work harder and take my mind of it was like telling a quadriplegic to relieve stress by running. Part of the problem was that I was unable to work hard. I couldn't even work up to my normal capacity, so how was I supposed to work harder? All suggestions like that did was serve to remind me of the things that I used to be able to do, and now couldn't.

In these situations, it is best to express your empathy, but also be truthful if you really don't know what someone is suffering through. Some of the best help I had was the presence of friends who stood by me no matter what. They didn't claim to have all the answers; they didn't really have any answers. They were just there. It is also important to anticipate emotions and irregular behavior. At the time I was feeling very self conscious anyway. The last thing I needed was for people to ostracize me while going through my coping process. A person grieving should not withdraw totally from social activities. I have had my days where I have not wanted to leave my home or room at school. But, when I was first diagnosed with clinical depression, my family doctor sent me back to UNI rather than stay at home in Mason City. He said that it was better than I at least try to stay in my normal routine, and that isolating myself at home would only make the problem worse. At the time, I didn't necessarily agree or disagree

with him, but in hindsight it was probably one of the most important things that I did. I kept going on with life, and didn't let my grieving shut me down completely. I made adjustments for my illness, but I didn't let it totally take over either. It was at this time that I most wanted to turn away from family and friends. I didn't want to burden them with my problems. If I was "going down", I didn't want to take anyone else with me. For some reason though, I didn't. Perhaps, this was because I have always relied upon my friends and family for support and been open with them.

Like death, grief is individual to each person. Everyone will cope with it differently. It will take each person a different amount of time to deal with their loss. Society often downplays dealing with grief and we think that people should "get over it", or "move on with things" more quickly than is possible.

A somewhat sobering fact is that a person never really fully recovers from a loss. After a death or a major trauma, life never really is "the same". I will never again live in the house I grew up in. I will never be able to look at my father the same way again. He will never again be a source of comfort and strength for me. Instead he has become an unreliable person who cannot even take care of himself. I will be able to cope with the loss. But things will never be "the same." This effect has been likened to the scar that remains after surgery. The intense, sharp, shooting pain will subside. However, there will always be a scar left behind. That area will always be a little tender, and subject to pain once again.

Loss associated with close family or friends is difficult because those people were so close. We cherished them because we shared so much of our lives with them. Our lives must go on, but without them. Now the activities which we used to enjoy serve of reminders of how things are different. This first Christmas without Dad was very tough. Everything was different. We were living in a new house. For the first time in my life, we did not attend a church service on Christmas. There were too many hurt feelings to do so. One of the happiest times of the year was just reminding us of how everything was different.

I have spent a great deal of the last four years hoping that life would “get better.” I now believe that it will, but only temporarily. There will be many more highs and lows in my life. In fact, this is probably only the tip of the iceberg. I’ve said before that the more I learn the less I really know. It is probably better that I don’t know the true magnitude of the trials life has in store for me. I don’t know if I’d have the courage to face all of my demons at once. But, I am now armed with the knowledge that the grief we experience in life is cyclical. The patterns I have been experiencing are normal, and that I must learn to incorporate them into my life.