

On Death and Dying Study Guide

On Death and Dying by Elisabeth Kübler-Ross

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Plot Summary

A classic in the study of death, dying and grief, this first effort by Elisabeth Kubler-Ross provides the first glimpse at the true feelings and experiences of people in the process of dying. Written in 1969, Kubler-Ross uses material gathered from her many seminars and interviews with terminally ill hospital patients and in a groundbreaking gesture, suggests to the reader that instead of ignoring, avoiding or isolating the dying patient, it is important to understand the stages of grief and to allow the patient to talk openly and honestly about his situation. In earlier times, death was not a subject to be discussed aloud, and was such an uncomfortable topic, that a dying patient was not free to share his feelings, anxieties, anger and transitions with even his loved ones. Kubler-Ross presents some new possibilities, that perhaps a dying patient feels lonely and isolated, and the awkward non-communicative way we treat the dying can be transformed to help the patient feel a sense of completion, comfort and peace at the end of his life.

With the help of four theology students, Elisabeth Kubler-Ross undertook a project that involved providing seminars at hospitals to help people with the process of death and dying. In addition, the group provided one-on-one interviews with patients and their families in an attempt to help them spell out their worries, frustrations, fears and undelivered communication. They found simply listening to the patients discuss openly and frankly the prospect of their own deaths was quite calming for the patients and perhaps, helped them to move on to the preparatory stage of grief, which coincides with the final stage of acceptance.

Death is a topic difficult for even the strongest people to discuss when it affects them personally. Often, terminally ill patients are avoided by their families, isolated and lonely, because it is too difficult for relatives to communicate openly about the situation. Kubler-Ross found patients are often eager to talk about what has happened to them, and the issues among their family members that may otherwise be left unresolved. Moreover, terminally ill patients wish their doctors would be forthright with them, and express their sadness and anger over the occasionally lax treatment they receive at the hands of nurses and other hospital staff.

The author's now-famous five stages of dying or grief, have been incorporated into hospice studies and, although they are perhaps presented too rigidly, they are based on the Kubler-Ross's extensive work with many terminally ill patients. Kubler-Ross wants us to know that, although there is no set, proper way to die, the stages of grief are fairly common, and apply not only to the dying patient, but the family as well.

The thrust of her message with this book is to encourage us to talk to the dying and listen to the dying patient, giving them whatever help they need to express their feelings and wishes, and helping them to resolve the final issues that are keeping them alive or in discomfort. Perhaps more importantly, we should not avoid a dying person, but sit with them, hold their hands, and just be a source of silent strength that will allow them to complete their process with dignity and in peace.

I and II

I and II Summary and Analysis

Kubler-Ross describes the increase in modern humanity's fear of death with the rise of technology and medical science. She feels that, although we are able to prolong our lives as never before, it has contributed to our emotional problems and inability to cope with the prospect of our death. We associate death with a bad act, or "malicious intervention" from someone else, or, at least a negative event. As children, we cannot grasp the reality of death, but as adults we continue to carry the fear of death with us, and experience grief, anger and shame when a loved one passes on. Kubler-Ross tells of death in her native Europe, where family and friends accept the transition quietly, not trying to make the dead look alive with embalming or makeup. Although pain medication and fluids are often called for, patience, friendship and support may be as important to one who is dying. We tend to hide the truth from children, and death is depersonalized, as we use machines and tubes to try to prevent the inevitable. The author feels we should spend more time focused on the experience and needs of the dying, paying more attention to the feelings of the patient than the equipment and intervention we assert in an attempt to, perhaps, mitigate our own fear of mortality.

In Chapter Two, in discussing our attitudes toward death, Kubler-Ross suggests our doctors are trained that prolonging life is a priority, as opposed to relieving suffering. The threats to our lives are more nebulous and can come out of the sky, such as nuclear holocaust, so we persist in making war on each other to deny our own mortality and defend against our own deaths. She notes we find it unfathomable for someone to go to war and survive on the front lines, only to come home and be killed in a car accident. Since we have fewer and smaller means of defending our own lives than ancient man, we tend to psychologically react more severely, trying to deny or master death. She feels if we study our attitudes toward death, we may be able to reach a more peaceful state both personally and globally, but fears of weapons of mass destruction have increased our fears of a "violent, catastrophic death." Kubler-Ross sees the decline in religion unfortunate, since we may no longer have the comfort of those beliefs when facing death. We cannot return to a simpler time when religion, death and technology were completely different, but she feels technology and science, although they are prolonging life, could also work toward more individual contact.

The author tells a story of a man whose life had become dependent upon a respirator, and whose doctor had gone to all lengths to save him. Her team, consisting of herself and theology students, helped the patient and doctor communicate honestly about his condition, which was a great relief to both of them. The team has continued to interview patients for years, allowing them to speak and be careful listeners. These sessions are at the core of Kubler-Ross's studies on death and dying.



III and IV

III and IV Summary and Analysis

Denial is the most common reaction to learning of a terminal illness. Most people are sure there must be a mistake about the diagnosis. Kubler-Ross sees denial as a buffer that allows the patient to "mobilize other, less radical defenses." She believes it is better to discuss death with a patient long before it arrives. Patients use denial to different degrees before accepting the finality of death, some never admitting or accepting to the very end. The reaction of denial is related to shock, and is a way of coping with the concept of mortality. An example is a patient who was so convinced she was cured by a faith healer of her terminal liver disease, that she became difficult to manage in the hospital, not behaving like a patient. The author feels the loneliness, fear and denial responses experienced by patients should be handled by others with acceptance and understanding, instead of contradiction. Respect, companionship and non-judgment allow the process to flow, and it is not always necessary to talk about the terminal nature of the illness if the patient is not able to accept it. The patient in Kubler-Ross's example knew somewhere in her mind she would die, but needed to fantasize and pretend to get through it because, having an unsupportive husband and small children, it was more than she could deal with in a straightforward way. Kubler-Ross suggests being with the elderly, sick and dying helps us examine our own reactions and behaviors.

In Chapter IV, we learn that the second stage of anger commonly follows denial, when a patient learns his plans and activities have been abruptly ended, and has to accept he will not be able to complete what he started. Anger toward hospital staff for doing too much, not doing enough, being busy and healthy and not sick is a common response to terminal illness. Ordinary life continues and the patient feels he is already being considered deceased by the rest of the world. An angry patient gets less attention and shorter visits because it is unpleasant to be around him, but the reasons for his anger may come out if someone will take the time to understand that the deprivation of communication, fear and frustration contributes to anger. If the companion or family is not afraid of death, and not defensive, we can listen to the anger and understand expressing it is a relief to the patient. It is important to understand that losing control of one's environment creates a huge amount of stress. Allowing a patient to determine the length of visits, the timing of meals and bed changes can give him a better sense of control. Kubler-Ross feels those patients who provoke rejection and anger in others are "the most desperate of them all."

In this chapter hospice workers conduct a long interview with a Catholic nun who knows she has had Hodgkins disease for years, but whose diagnosis went unconfirmed and unclear for a long time. She describes how she has been treated by hospital staff, who have assumed she simply had mental problems, and how the psychiatrist she finally agreed to see is the only one who recognized the physical nature of her illness. She became a nuisance at the hospital, having been admitted eleven times, and serving as



an advocate for patients whose needs she felt were being ignored. The nun's story is extensive, and includes isolation, her friendship with a Jewish man who made her examine her faith and her anger and hostility toward other people, including her own family. The nun also discusses the issues of patient dignity and how difficult it is to have to beg for what we need when we are ill. Allowing her to speak freely about her feelings and her challenging years of being hospitalized allow her to finally come to terms with her anger.

V and VI

V and VI Summary and Analysis

The third stage is bargaining, which is usually an attempt to postpone the inevitable. The patient may promise one thing in exchange for another day, less pain or anything else to relieve his situation. Many terminal patients promise to dedicate their lives to God in exchange for additional time to live, and some promise their body parts to science in exchange for their doctor's extra effort in prolonging their lives. Kubler-Ross suggests bargaining could suggest unresolved guilt, and a patient's pleas for more time should be listened to carefully to help him gain an understanding of his irrational fears.

In Chapter Vi, Kubler-Ross describes the fourth stage of dying as one of depression from the realization of loss. Whether it is a lost body part or the loss of hope, depression usually replaces any denial or stoicism for the terminally ill patient. She describes two different types of depression, one being a "reactive" depression and one being "preparatory," or part of the process of preparing for separation from the body, and both are often accompanied by shame or guilt. Having the logistical details resolved regarding the family's well-being and placement of the patient can relieve depression.

However, although it may be helpful to try to cheer the depressed patient with happy thoughts of the family functioning well without her, cheering up a patient who is in preparatory depression is not as effective. It is important to let him express his sorrow at the total loss he is about to endure, and sit quietly with a patient. Sometimes encouraging a patient defeats the process of his preparing for the finality of death, creating a discrepancy between what the patient wants and what his family wants.

This chapter contains another extensive interview with a terminally ill patient involving the doctor and chaplain. Mr. H is married to a woman who values achievement and earning ability above most everything else. His illness and impending death will not really phase her positive lifestyle, in his opinion. This patient has lost his parents, a brother and a 28 year old daughter in a short period of time, and is now depressed because what makes life worthwhile for him is not the same as for his wife, whom he admires, but who does not appreciate him. The patient was described as uncommunicative, but when given the opportunity to talk, he opened up and talked at length about his relationship with his wife, the hospital services and his condition. Kubler-Ross realizes he had been contemplating the meaning of his life rather than focusing on his cancer, and his depression was connected to his unresolved grief for his daughter and his hopelessness about communicating with his wife.

When the hospice team discussed Mr. H's feelings with his wife, she was able to point out his admirable traits, and later repeated those to him, perhaps with a greater appreciation of him.



VII and VIII

VII and VIII Summary and Analysis

The fifth stage of dying, according to the author, is acceptance. During this stage the patient, after having gone through all of the other stages, now wants to quietly retreat to his fate, much like a child returning to the womb. Some patients fight against this stage to the end and in the case of abrupt and sudden death, do not have the opportunity to reach acceptance. This chapter contains the story of Mrs. W. who was ready and prepared for her death, but whose husband could not let go and interpreted her detachment as rejection. He arranged for an additional surgery to prolong her life, and Mrs. W., normally a dignified woman, responded with a psychotic episode. The author's point, again, is that it is important to listen to a dying patient's wishes and needs, and try not to let our own fears and sorrows interfere. Kubler-Ross has observed that patients who are encouraged to express their feelings during the process generally die with more peace and dignity. The author includes two interviews in this chapter with patients who are working toward reaching the stage of accepting their deaths.

A dentist with terminal cancer reveals he maintains hope for a cure, but is comfortable in his faith that the will be with "the Lord" when he dies. The interview illustrates the different stages the patient, his wife and son have moved through from first learning of the fatal nature of his disease, through accepting the finality of his death, while still looking into possibilities for treatment. It is not clear whether the author is promoting Christianity as a solution, but the pattern in her stories is that of faith in Jesus being the key to peace.

In Chapter VIII, we learn most terminally ill patients hold out a certain amount of hope, either for a cure, or to be a special patient, an exception to the norm. Hope nourishes the soul at the darkest times, and doctors who allow for expressions of hope are more trusted. Often, the miracle for the patient turns out to be the loss of fear and the peace of acceptance, rather than the obscure medical cure. Further, Kubler-Ross stresses we should not give up on terminal patients at the risk of them giving up on themselves. Some patients made some kind of comeback after being interviewed. All of the patients interviewed appreciated the opportunity to express their feelings, and some wanted to meet once more with the author and their families in order to "drop the facade," and speak openly about their conditions. The author suggests we should talk as openly about death as about the expectation of a new baby, since many depressed patients opened up and lightened up after being encouraged to communicate freely about their impending death.

An interview with a patient called "Mr. J." helped teach the author that it is not appropriate to try to make these sessions a teaching opportunity, but better to hear out the patient's philosophy of life and simply be there to listen, allowing the patient to decide when and if he wants to discuss dying. This patient appreciated small moments, or "bonuses," when he would be interested in something, like a television program or

reliving a memory, that might take away his consciousness of his illness. The author detects this patient's anger over being a good person and going through a lot, only to be rewarded with a terminal illness. However, the patient held onto hope until he died.

IX

IX Summary and Analysis

Chapter IX addresses the issues related to the families of terminally ill patients, including the forced changes and adaptations of having a member no longer functional. The author notes men sometimes revert to children when their wives become ill. She feels it can be good for a patient when the family goes on an outing or continues some activity that indicates their lives will go on. Non-communication about impending death is often associated with the family's guilty feelings, but honest communication about the situation can ease all parties involved. Kubler-Ross describes a young girl who gave up her own life to spend every minute with her dying mother. Her mother, unable to speak, was relieved when the daughter agreed to take a part-time job and not spend so much time in the hospital room.

A farmer named Mr. Y was allowed to see his wife for only five minutes every day in a large city hospital where he hoped she would be cured. He expressed his anger and loneliness, since they had been very close for many years. The author suggests there should be hospital support for family members, and perhaps family should not spend an inordinate amount of time with the patient, but notes we cannot judge families for their behaviors, no matter how unorthodox they may seem. The immediate families of terminally ill patients experience the same stages of grief as the patient, but can make it easier for the patient and for themselves to enter preparatory grief if they are honest and communicative with one another.

The family should understand a patient's need to withdraw from interpersonal relationships as he goes into the final stages of preparatory grief. We must also try to know what might be frightening the patient or keeping him from dying, such as one woman's fear of worms, who had only to be told she would be cremated, allowing her to die the next day. It is important to understand underlying family dynamics when a family member is behaving in an inappropriate way toward the dying patient, whether it is making poor decisions or holding on too tightly. A patient called Mr. P. helps the author understand that sometimes the expectations and wishes of the family for the patient to continue living causes the patient to feel guilty and anxious. She feels family should not use a dying patient to fulfill their own needs and wishes, but should respect and consult with the patient.

Once the family member has died, the other family members must go through all of the emotions elicited by this reality. After the details are done and the relatives have gone home, family members need to talk and ruminate about the lost loved one, and sometimes even talk to the deceased. Some need to accept the reality gradually, and take their time facing the loss.

Up until age three a child has concerns about separation, and after that, concerns about mutilation, and death seems like a temporary condition. After the age of five a child can



see death as a being who takes people away. Only after nine years old does the child begin to understand the biological process. The child might mourn loudly, or feel responsible, or secretly think the deceased will return. Again, Kubler-Ross emphasizes the need to listen to the feelings of the person who is hurting, and share in them whether they are rational or not. If we do not tolerate their anger, we are contributing to their prolonged grief, which can result in emotional illness.

X

X Summary and Analysis

This chapter is a series of interviews with terminally ill patients. Mrs. S., a 49-year old cancer patient, reveals she has suffered a number of losses in her life, including the death of a young child, the death of a family doctor, and desertion by her parents and a spouse. She lives her life for her two sons, and needs to share her concerns with someone willing to listen. Her neighbor has become like a sister to her and has helped her with her children and her illness. The opportunity to talk about her past and her illness seems to help her tremendously.

A 17-year old is told of the seriousness of her condition not by her doctors, but by her parents. Her faith that her fate is in God's hands is what sustains her, and she senses a closer relationship among all her family members since she became ill. She is glad to have known about her condition from the beginning so her friends and family can face her. She speculates death is like a reunion, or going home. Later, when the team interviews the girl's mother, they learn this family has openly discussed the girl's impending death and her siblings have tried to treat her the same as always. The girl has already made her own funeral arrangements and knows she will be gone soon. Her mother discusses the inattentiveness of the hospital staff, but overall has a positive, cheerful and open-minded attitude, bolstered by the family's strong religious beliefs.

A mother of a small daughter expresses concern that in telling her daughter of her condition, she may have given her unfounded hope. She is frustrated the doctors do not give her information on her condition, and that she is treated poorly during x-rays. She is concerned she is the one responsible for her son, who is retarded and emotionally ill. She considers perhaps the elderly parents should be put in a home, or her son institutionalized. Again, this woman attributes her happy marriage and strength to her family's religious faith. She shares how much it helps to have people with her, but is realistic one must be alone in this process, too. A concern for her is that the pressures of her home life will have an additional impact on her health. There is a theme in this chapter regarding patients whose responsibilities to their families make the process of dying extremely worrisome. Women, in particular, who have spent their lives trying to be all things to everyone have a difficult time letting go until they know everyone will be taken care of.

An extensive interview with one courageous female patient who does not complain about her situation is fascinating. She feels sorrier for the doctors than for herself, and assumes when it is time for her to die, she will know it and will think about it then. In the meantime, she keeps her mind busy thinking of others and keeping her mind off of herself, equating complaining with death, based on her observations of family members. In a sense, she stays in denial, but only as a convenience until death has actually arrived. She confirms the response to death is an individual thing and everyone does it differently.

XI

XI Summary and Analysis

The hospital staff, specifically the doctors, initially show a somewhat hostile resistance to Kubler-Ross's seminars on death and dying. Only a small number of doctors are receptive: those who are older and lived in a time prior to the development of the defense mechanisms we now have against death, younger doctors who attended the seminars regularly, and those whose specialty area is caring for the terminally ill. Author Cicely Saunders, who was once a nurse and now a doctor, confirms most terminal patients know they will die whether or not they are told, and recognizes the importance of a doctor's willingness to sit and listen to a terminally ill patient. Kubler-Ross notes patients who did not request the seminar were often patients of those doctors who understood their needs and were supportive of the seminars. Most doctors, however, did not want Kubler-Ross and her staff to contact their patients, revealing their lack of awareness in this area. The doctor most hostile was one who told his interns they were not to speak of any serious aspects of the patients' illnesses, and fully rejected the seminars on their behalf. Doctors unable to be forthcoming and open to the patient are the ones most opposed to this kind of work, as they feel it undermines their treatment. Doctors who actually attended the seminars contributed and learned greatly. Nurses generally had the same initial reactions, although some were more empathic with the patients and resented the doctors' treatment tactics. They were also supportive of the doctors who had the courage to hear criticisms of their treatment and bedside manner.

In a ward of the hospital where terminally ill patients were often left alone, the nurses were encouraged to express their opinions, which were generally that these patients were a waste of their time and energy, since they were dying anyway. After training with Kubler-Ross, they have become advocates for the dying and even teach her classes.

Some clergy who have only been able to turn to scripture or teachings to comfort the dying have come to realize through these seminars how they use those tools as a way to avoid the real issues. The author affectionately describes one of her theology students who was facing a possible malignancy, and whose experience enriched his empathy and understanding. The author feels once the highly resistant staff members were able to analyze their defensiveness, they became an asset to patients and other workers. Many of the students signed up for the author's program had their own issues to resolve and learned how to understand their own role in the patient's and families' "psychodramas." In a sense, the students went through their own group therapy in learning to help the terminally ill.

Most terminally ill patients welcomed Kubler-Ross's program, and were relieved to speak their feelings and shake out their unrealistic fears. This type of program can assist the dying with their hopelessness, the monotony of waiting and being ill, and the vagueness with which they are often approached. They are also made to realize their communications are important, and they do have something to contribute even at this

late stage. The seminars gave the patients a reason to dress up and break the boring hospital routines. Many discharged patients stayed in touch with the seminar team; they note extreme appreciation of even the smallest kindness from staff. Patients, having left their thoughts behind on tape, may feel they have left something of themselves after death. The seminar allows the patient to drop the facade of denial and talk openly.

Kubler-Ross feels what the seminar team learned from patients was that most of them are aware of the seriousness of their illness whether or not they are told, and welcome a breakthrough from the well-intentioned facade maintained by staff and family. All appreciated venting their feelings, but they also know when they have had enough. Patients who have had meaningful and productive lives are more accepting than those who have spent their lives controlling, accumulating and having few interpersonal relationships. Kubler-Ross humbly notes a change in the hospital atmosphere and notes hospital staff now seek consultations.

XII

XII Summary and Analysis

Willingness to listen and share the concerns of the dying is obvious from these studies. An open initial interview helps the patient know there will be no fear of using the word cancer or death. It is important to remember why some patients may be hanging on to life, whether over some imagined guilt, fear or unfinished business. Kubler-Ross describes at length an elderly Mr. E., who was not terminally ill, but suffering from a sense of loss of control over his life. He also carried guilt and anger toward a deceased wife who had left him, transferring those feelings onto the hospital staff. After understanding his own behavior, his demeanor changed, and he felt he could now face his death with "more equanimity."

The author has seen patients with similar illnesses form informal groups to provide companionship and an open forum for one another, counseling each other through the process and sharing their stories.

Toward the end of life, patients enter a quiet state as they approach their death. This state is the most difficult for those who are faced with the separation. Having a therapist or counselor sit quietly with the patient when he passes on can alleviate the guilt for loved ones who may not be comfortable with being present. Kubler-Ross describes the "silence that goes beyond words" as a peaceful transition from life "neither frightening nor painful, but a peaceful cessation of the functioning of the body." The therapist who witnesses this realizes the uniqueness of each person's life.



Characters

Elisabeth Kubler-Ross

The single most important character in this book is the author herself. While revealing little about her background, this ground-breaking project was clearly within her sphere of specialized interest and was successful only due to her determination to make a difference for the terminally ill and their families. Her European background, where death is discussed openly and handled in a healthy way, was at odds with the cultural customs she observed in this country. Almost single-handedly, Dr. Kubler-Ross broke open this field for Americans and ultimately, changed the way we deal with this sensitive subject.

The author does not reveal much about herself or her background, but her presence in every aspect of this book is obvious. She is at the head of the study, requested by four theological students with whom we are never made quite familiar. Clearly, she was the creator of the multi-disciplinary team that constructed and delivered the interview questions, and drew conclusions and opinions from them. This book provides a somewhat brief recap of two years of weekly interviews with terminally ill patients. Kubler-Ross, in her professional capacity, analyzed the team's data, drew conclusions from it, structured it into usable prose and wrote this book as an offering to those within and outside of her profession. However, she is not simply a scientist, but was clearly moved by what she learned from the patients and their families, as evidenced by her dedication to the memory of her father and another deceased loved one.

Also a wife and mother, Dr. Ross's unique interest in this field of study led her to write many more books after this initial groundbreaking work. Although she credits the students, the clergy and others who worked with her on this project, it was clearly her impetus that made it successful. Originally designed to help theological students write a paper, the project blossomed into a full-blown study, which launched the author's career in this field. It takes a tremendous amount of dedication and stamina to work with the terminally ill and their family members, week after week, knowing the finality of the situation and observing the emotions a death in the family elicits. Kubler-Ross shows a tenacity of character, a deep compassion that goes beyond surface emotions and the true heart of a scientist, as she deals with this extremely difficult subject in a clinical, objective and compassionate way.

Mrs. K.

A patient admitted to the hospital for a terminal liver disease, Mrs. K. was convinced a faith healer had completely cured her. She is used by Kubler-Ross as an example of the kind of denial patients can experience when they learn their lives are going to end. Mrs. K. had two small children and her mind was unable to fathom the thought of her impending death. She was readmitted to the hospital and wavered in and out of doing



what she was instructed and eating recklessly against her doctor's advice. She was giggly, silly and "inappropriately cheerful" as she went about the hospital talking to people and doing little projects, claiming to be perfectly well. She wanted people to notice and comment on how well she was, and could not be convinced otherwise. Her husband was objective and not particularly sympathetic, which may have contributed to her delusional behavior. With an unsupportive family and her veiled threats to commit suicide by eating too much, this patient was allowed to be in denial as long as she needed to be in order to work through her fear and pain. As she eventually became weaker and more withdrawn, she showed signs she actually knew she was going to die.

Kubler-Ross also describes how this patient was avoided by the nurses because they felt there was nothing they could do, leaving her door closed and ignoring her. This isolation is one of the issues the author addresses throughout the book, as she describes the feeling of loneliness when we deny our company to those who are dying.

Mrs. W.

A 58-year old woman whose husband was devoted to her, Mrs. W. was in pain, tired and ready to die. However, her husband was unable to let her go or to accept her death. Mrs. W. felt the need to care for herself as long as possible, but felt her family would be able to make it without her. She was at the stage of acceptance, feeling her life and marriage were good and she could do no more than to be left alone and die peacefully. However, her husband, who had not reached the acceptance stage, took her need for solitude as a sign of rejection and wanted to prolong her life as much as possible. He consulted with other doctors regarding an additional surgery, which Mrs. W. did not want. She became more sick and anxious and when the day of surgery arrived, she went into a psychotic state, unable to simply tell the doctors she did not want the surgery. When she was returned to her room, the surgery canceled, she asked Dr. Kubler-Ross to talk to her husband to help him understand she was ready to die. Her husband had not been able to understand this, even though she tried to communicate it to him. After sessions with the author, he began to consider his wife's needs rather than just his own. She wanted him to stop pretending she would be alright, and, although it was difficult, he finally let go of hope for her. She was finally allowed to die with dignity.

Mr. H.

This patient was a man portrayed as uncommunicative and difficult, but he talked to the interview panel for over an hour, his strength renewed by communicating. His interview was related in the chapter on depression. In his interview the team learned he had lost a daughter as well as his parents, and had now lost hope for himself. The interviewers realize his depression is not so much over his own condition as the fact he is still grieving the loss of his loved ones, and he is sad his wife judges and compares him to the men she knew when she was young, who were hard workers. She sees him as weak and not having met her expectations, and feels nothing will change after he is gone because he was basically useless. Mr. H. knows she feels this way, and this is a



major component of his depression. When the interview staff talks to his wife, she confirms these feelings, but when they are paraphrased back to her, she jumps to his defense, realizing there are very good qualities about him. His wife agreed to give him credit for the assets he did have and actually offered to help him by picking up some of his church work, for which she had formerly shown no respect. Her change of attitude seemed to end his depression, and he was eternally grateful for Kubler-Ross and her ability to get his wife to communicate. His depression stage ended when he was able to resolve these problems and move into acceptance of his death.

Rabindrinath Tagore

Clearly the author's favorite poet, the Indian Tagore's writing appears at the beginning of each of her chapters and is always relevant to her topic. He writes in beautiful, descriptive and symbolic language about the beauty of life and death, and he has a simple insight into our existence that Kubler-Ross clearly respected. In her opening chapter, she uses Tagore's verses from "Fruit-Gathering," wherein he asks for fearlessness, strength and patience in the face of pain and death. Each chapter's verse is inspiring and colorful, and makes the reader want to know more about Tagore. Without making any mention of it, Tagore's work has inspired Kubler-Ross enough to use it throughout her book.

Dr. G.

Dr. G. was a dentist interviewed by the team. He is a war veteran whose doctor did not tell him the nature of his condition. His 24-year old son, however, had the courage to tell him, even though his wife later claimed she had told him. Dr. G. claimed to be at complete peace with his prognosis, and claims to be totally reliant on his faith in his religion for all things. The depth of his religion might be said to be the thing that kept him sane and peaceful throughout this process, but as a reader, one might perceive his continuing denial and use of his religion as a way to displace the burden of his illness, not being able to carry it alone. He is continuing to seek other treatment because he believes the "Lord" can heal him, indicating an ongoing hope rather than true acceptance. He seems to be a wonderfully healthy man emotionally, however, and his story is included in the book's chapter on Acceptance because he is a model of peaceful dignity in the face of death.

Mr. J

His case used as an example of hope in Chapter VIII, this patient is an example of a person who never gives up, even at the very end of his life. Although he is aware his illness is terminal and there is no known cure, he feels he had a good life and reviews in his mind the pleasant things about his childhood, and recognizes what he called "bonus" days. He is so grateful for any small pleasure, and distracts himself from miserable feelings or thoughts. He still hopes something may cure him and he may walk



out of the hospital some day, but he spends time appreciating the hospital staff and his happy memories. He knows his good and bad times come in cycles, and feels lucky when he goes into remission. He also hopes for a drug that might relieve his suffering, and is hopeful until the day he dies.

Mrs. F. and her daughter

Mrs. F was a terminally ill woman whose daughter had quit her job and was spending every day, all day with her mother in the hospital room. Her daughter rarely offered any affection or communication, but stayed as if it were her duty to do so. She gave up everything about her personal life to be with her mother and, yet, was extremely uncommunicative. Once the team interviewed the daughter, they realized she had been experiencing terrible feelings of guilt and was trying to resolve them by her constant presence in her mother's room, getting little sleep and foregoing her normal life. The young woman felt she had been deserted by her mother, and felt badly for resentment and ambivalence toward her ailing mother. When she finally realized her mother needed some space from her, she got a part-time job and began spending more time outside the hospital. Her mother was able to die peacefully, after finally spending some meaningful time with her without the feelings of guilt and obligation.

Mr. Y.

In the chapter on families of the dying, Mr. Y. is described as an elderly farm-type person, who brought his wife into a big city hospital to the intensive care unit. He was totally unfamiliar with the city and was extremely uncomfortable in that environment, struggling with the expense and trying to find an appropriate place to sleep. He was only allowed to see his wife for five minutes every hour, and was spotted by one of the students as looking like a lost soul. He expressed his anger to the interviewers toward the nurses who allowed him so little time with his wife and made him feel he was in the way. He and his wife were so close there was no question of leaving her there without him. The research staff helped him find more comfortable quarters, but were not able to help him much more than that.

Mrs. P.

In the chapter reviewing reactions to the seminar, Mrs. P. is used as an example of a patient who caught in the middle of a personnel change and with no idea who her doctor was. The patients all seemed to have some complaint about their treatment in the hospital. The team tries to help her out with her problem, and it causes a political upheaval in the hospital, with the doctor accusing Kubler-Ross's researchers of taking his patients. Dealing with all kinds of hospital issues, this chapter highlights several patients who are caught in the web of the doctors' strange beliefs about honesty, the hospital's policies and the group's shakeup of the entire system with their honest approach and penchant for helping patients speak openly about their illnesses.



Objects/Places

Seminar appears in non-fiction

A discussion group, or colloquium, held for the benefit of doctors, nurses, support staff, clergy as well as terminally ill patients and their families in the hospital, where Elisabeth Kubler-Ross and her staff of students conducted research. Patients were personally interviewed by a small team behind one-way glass and freely chose whether or not to attend. The seminar eventually evolved into an accredited college course.

Chicago Theological Seminary appears in non-fiction

The school of the students that approached Kubler-Ross to help them with their paper on the biggest crisis in human life. At the time the book is written, the team still sees one terminally ill patient per week and interviews him or her, tape recording the dialogue.

Interdisciplinary Hospital Personnel appears in non-fiction

The Catholic hospital where Kubler-Ross's interviews were held behind a one-way mirror so that an audience could observe and the patient could be interviewed in a relatively private setting. The nurses were often nuns, and there were clergy present. Thus, the interdisciplinary group benefiting from the interviews and seminars consisted of doctors, nurses, psychotherapists, theological students and support staff.

Five Stages of Grief appears in non-fiction

Kubler-Ross determines most people pass through five basic emotional stages once they learn they are terminally ill. The first stage, denial, involves the inability of our brains to embrace the idea of our own deaths, and our tendency to deny the truth of what we have been told. The second stage, anger, usually sets in when we think about how unfair it is to have our lives interrupted at such a time, and we wonder why this does not happen to someone else instead. The third stage is bargaining. This is when we make secret promises to God or the universe that we will change in some way or will devote ourselves to service in exchange for more time. The fourth stage is the inevitable depression that sets in once we realize everything we have and hold dear is going to be lost to us forever. This is the most difficult stage and requires a great deal of patience and support from family members. The final stage, acceptance, is one some people never reach or do not have enough time to reach. It usually comes with a quiet understanding and personal withdrawal as we prepare for the final event of death. It is not usually sad or morose, but is matter-of-fact and calm, and is best reached when all emotional and logistical issues are resolved.



Desensitization appears in non-fiction

In our technological age, we have become desensitized to the needs and feelings of patients, focusing more on saving their lives with medicine, machines and equipment than taking into account the human being. "He may cry for rest, peace, and dignity, but he will get infusions, transfusions, a heart machine, or tracheotomy if necessary." Kubler Ross suggests this mad, depersonalized rush to save lives may be symbolic of our defensiveness about death, and a way to repress the anxieties we feel around terminal illness—denial of impending death and placing our faith in machines rather than people.

Malignancy appears in non-fiction

Whether or not a tumor or cells are malignant, or cancerous, is a question of great importance to an ill patient. Malignancy does not always mean a death sentence, but it can make the prognosis much more serious and often fatal.

Therapy for Terminal Illness appears in non-fiction

Kubler-Ross encourages the ability to sit quietly in the "silence that goes beyond words" with a patient who is dying. The only therapy that may help alleviate pain and suffering is facing the fear, resolving logistical issues, understanding our own feelings and finally coming to a peaceful acceptance of death.

Silence That Goes Beyond Words appears in non-fiction

This is the silent time Kubler-Ross describes that takes place just before death, when the dying patient needs only a silent companion nearby. The patient is finished with worldly things and thoughts, and wants only to be silently withdrawn and focus on the process of death.

Group Therapy appears in non-fiction

The author does not conduct group therapy sessions, per se. However, she notes patients with similar illnesses informally gather together to discuss their specific problems and issues, and feels group therapy of this kind might be helpful to terminally ill patients.

Social Worker appears in non-fiction

Social workers for terminally ill patients are employed by state or county agencies, and are assigned to help the patient deal with his or her business details, such as insurance



and family issues, locate needed equipment and facilities, and help the patient in any manner as they encounter the problems of being terminally ill. Today, many of these details are handled by local hospice organizations.

Chemotherapy and Radiation appears in non-fiction

Two treatments for terminal cancer are the ingestion of medicinal chemicals intended to destroy cancer cells, and radiation of the areas where a tumor or cancerous tissue is located to diminish and destroy cancer cells. Most of the patients seen by Dr. Kubler-Ross's team are in some stage of either or both of these treatment regimes.

Preparatory Grief appears in non-fiction

This type of grief is described as a quiet, introspective process when a patient is trying to prepare himself emotionally for acceptance of his mortality. It is not the same as the depression experienced over unfinished business or emotional upset, but a more constructive and deeper state of grief.

Discrepancies in Expectations appears in non-fiction

The terminally ill patient often finds himself feeling obligated to live on due to the optimistic expectations of his loved ones, who want him to come home and things to be normal again. Often, the patient only wants to let go and die peacefully, but feels pressure and obligation from his family members to hold on.

Suicide appears in non-fiction

Suicide is often contemplated by the terminally ill patient as a way to end his suffering and have control over the outcome, rather than spend days and dollars in pain and anguish waiting for the body to die of its own accord.

Communication appears in non-fiction

The key to a peaceful and dignified death is the ability to get a patient to communicate his feelings. Often a patient feels anger and hostility, and perhaps feels guilty for having those feelings. A good therapist can help a patient work through confusing feelings so the family and patient can communicate maturely and clearly about the impending death.



Decathexis appears in non-fiction

This is a psychological term that means a withdrawing of psychic energy from something to which we are attached. Kubler-Ross uses the term to describe the withdrawing process of preparatory grief a dying patient enters as he prepares to leave everything and everyone behind.

Faith appears in non-fiction

Many terminal patients rely on their faith to help them through the process of dying. Faith is a belief there is a larger, stronger force at work, and one does not and cannot control his own destiny, but relies on this force for the ultimate outcome of peace and salvation.

Fatal Illness appears in non-fiction

An illness that inevitably leads to death, usually one for which no cure is known.



Themes

Honesty Makes Death Easier

A theme woven throughout this book is that the commonly felt need to protect the terminally ill patient from the truth about his condition often makes the natural process of dying more complicated and painful. Much of the anger, hostility and negative emotions expressed by patients is connected to unspoken truths. Thus, not speaking the objective truth about death can add to their illness, frustration and inability, in fact, to die.

Kubler-Ross's seminar team was able to help many patients identify the real source of their anger, which is often directed toward hospital staff and doctors. The roots of much of this emotion is connected with confused messages, unnecessary guilt or remorse, fear over unfinished business and a number of issues that can be resolved simply by identifying their source. However, withholding any discussions about death can cause a patient to feel completely alone and isolated, as well as afraid, complicating the natural emotions he already must experience.

Kubler-Ross suggests the patient always be told the truth about his condition, no matter what. Whether it is told to him by family members or the doctor, it is important the facts be laid out for the patient to deal with constructively. If we learn to listen to the dying patient without trying to deceive him, we can assist him to depart on a more positive, loving note, and perhaps better appreciate the life he has lived. Suspecting he is terminal and that he is being lied to is a violation of the patient's dignity and keeps him from exploring and making decisions about his transition.

External Expressions Often Hide Internal Feelings

One of the patients who underwent the author's seminar sessions was a terminally ill woman whose death was unexplainably prolonged. Her attitude was negative toward the hospital staff and her family's funds were about to be exhausted from her extended hospital stay. When one of the counselors helped her reach the root of her anger, they discovered that underneath it was actually a phobic fear of worms. The patient knew this was a silly idea and an unfounded fear, but nonetheless, the fear of worms eating her body had troubled her so deeply it was affecting her ability to die. When her daughter offered to have her body cremated, the woman died within twenty-four hours.

When a patient sees the hospital staff moving, working pain-free, smiling, and going home to their families, it can agitate them because they know that because of their illness they are being denied the simple luxuries most people take for granted. This can result in hostile feelings toward the staff, and the patient's sense they are not being cared for well enough. In addition, due to busy hospital conditions, having to beg for relief from pain can be a humiliating and upsetting experience which looks, on the



surface, like hostility. Hostility is often the result of a complex set of emotions that have little to do with the patient's death, but are more grounded in old hurts and resentments that have not been forgiven or dealt with.

During the last phase of dying, a patient will need to be alone and quiet, and this is sometimes interpreted by family members as rejection. In turn, the patient may become irritable that the family will not allow them to die peacefully, constantly trying to cheer them and give them hope. Once we realize this withdrawal is normal and healthy in terminal patients, we will understand that sometimes all they want and need is someone sitting next to them, quietly holding their hands or simply just being there as their lives subside.

Death is a Natural Process

Kubler-Ross emphasizes we have come to see death as something we should prevent at all costs, and at times our resistance to death only prolongs the patient's pain. We are so determined to keep people alive on machines and with medicines that they, perhaps, do not even want. By defining and describing the stages of dying, Kubler-Ross breaks new ground by reminding us that all these stages, no matter how we live them through, are normal and natural parts of the process.

Kubler-Ross reminds the reader death is just as much a part of life as birth is. In our technological society we try to maintain the patient's physical systems but tend not to pay attention to the patient, himself. All of the busy medical activities taking place around an ill patient's body disregards the fact he has a soul, feelings and desires about his own health.

In earlier times, when our resources were more limited, death was more accepted and treated more as a natural function. We cleansed the bodies of our dead and buried them respectfully. Now, we try every kind of technology to save the body, even prolonging life beyond the conscious state to maintain a vegetative state in the hope the person might return to life. Although it is marvelous to think about what we are able to do for a patient, it is also ridiculous deny our loved ones the natural aspects of death, at the expense of their emotional well-being.

Communication Allows for Mutual Learning

Elisabeth Kubler-Ross's seminar approach clearly helped many patients discover the bases of their own feelings, including rage, sadness, hope and loss. Assistance from clergy with matters of faith, assistance from a psychotherapist in clarifying confusing feelings and assistance from other patients provided a tremendous amount of constructive, helping to clear the way for these patients to accept their deaths with peace and dignity.

However, working with the patients also provided the seminar team an astonishing amount of knowledge about the things we hide, the way people perceive their



caregivers, the number of doctors who have such problematic issues with death that they cannot tell their patients the truth, and the great need of patients to just have a good listener near them. The patients whose religious faith was affected by their illness provided enlightenment to the team, one nun in particular who had used the opportunity to truly define and own her own religion. Patients who seemed irrational to the hospital staff and were finally able to discuss their feelings, shed a tremendous light on patient care for the nurses, doctors and support staff. Finally, those of us who will go through this process with loved ones have much to learn from the patients, whose insights and opinions were heard and recorded, perhaps, for the first time. Kubler-Ross's audience for this book is professionals and laypersons, alike, and is based on the knowledge she gained from the patients themselves in these interviews.

Style

Perspective

Elisabeth Kubler-Ross writes this entire account of her experimental research from her own perspective, but includes quotes and documented interviews from patients and other people who participated in the study with her. Having undertaken the experimental study at the request of college students, the author seems excited and surprised by what she has observed and this study, in fact, launched her writing/research career into death and dying. Her intrigue with this study is clear from her enthusiastic writing about it and, as most people know, she later conducted studies of people who had actually experienced death and lived to talk about it. This book, however simple the perspective, opened up a field that had been tightly closed due to cultural restrictions and medical implications.

Kubler-Ross was the first to publicly discuss the importance of talking openly with terminally ill patients, based on the perspective she gained through this study. All of the advice, philosophy and opinions expressed in this book are the author's own, based on the results of this lengthy hospital study. In addition to discussing the patients' views, she also expresses the perceived attitudes of others, including doctors and hospital staff. At times, these opinions are based upon such things as not getting a doctor's response for ten days after having requested to see a terminally ill patient.. Although perhaps correct in her assumptions about others' attitudes, Kubler-Ross speculates and assumes frequently.

There is an abundance of material quoted in this book from patients who are extremely religious. It is not clear what the author's religious stance actually was at that time, nor is it clear what her intentions were in including so much discussion of Christian values. She does not surmise that religious people have an easier or better experience with terminal illness, but includes enough Christian dialogue that there is an indication she was extremely religious herself. However, the fact the experiment was held in a Catholic hospital may have contributed to that aspect of the interviews.

Tone

Elisabeth Kubler Ross, in her attempt to write a book that would appeal to doctors, medical professionals and the general public, created a mixed tone of scientific objectivity with an emotional appeal to those dealing with the terminally ill. Her professional background seeps through with her occasional use of a medical term (such as "contraindicated"), but for the most part she keeps this book simple to read and comprehend in her hope it would be read by families of terminally ill patients, as well as professionals. Since her seminars were attended by doctors, orderlies and support staff, she was addressing a very wide-ranging audience, and does a fairly masterful job of not allowing the book to become too boring or too clinical.



Death and terminal illness involve substantial agony, sadness, remorse, fear and guilt. Although we are allowed to experience these emotions through the interviews with patients and their family members, the tone of the book remains somewhat clinical, since Kubler-Ross was conducting a study, which eventually was approved as a college course. The seminar was constructed as a way to teach the students who sat behind the one-way glass about the feelings and experiences of the terminally ill. Thus, the interview questions are somewhat pat and formulaic, however, the team did not restrict the patients' time in answering, and allowed them to considerably wander in their discussions.

Kubler-Ross's tendency to categorize the stages of grief is a result of seeing many patients and drawing conclusions about the similarities she observed in their behaviors. Although the stages she describes have been disputed as being too pat and too formulaic, she was the first to identify them, name them and give them any kind of sequence. In this sense, she was a leader in this field and the first to really delve into sensitive issues unexplored up until that time.

The author's European background comes through in the book in subtle ways. Her insight into the need for more honesty and objectivity about death is a result of her simple upbringing in a rural European setting. She is not overly sympathetic or subjective about the dying patients, but is practical, straightforward and somewhat blunt in her ideas about how they should be addressed. Kubler-Ross 's writing reveals she is not a writer, but a scientist who writes. She writes as though she is speaking to her reader directly.

If we can assign a goal to this work, it may be that Kubler-Ross hoped to enlighten us about how to have a peaceful and dignified death, the preferable way to transition from this life.

Structure

Although intense, this book is only 299 pages long, and is divided into twelve chapters of uneven lengths.

Kubler-Ross sets the stage for her study with her opinions about the misguided attitudes we have in this country about death, and explains how her interview group came together and how they structured the hospital seminars.

She then divides the book into chapters addressing what she considers to be the five stages of dying, which are denial and isolation, anger, bargaining, depression and finally, acceptance. She adds a small chapter on hope, goes on to a longer chapter addressing the families of terminal patients, adds a chapter of various interviews with terminally ill patients, a chapter on reactions to the seminar, and a final chapter on psychotherapy for the terminally ill. This condensed book covers a wide range of topics in a very narrow format and gives the sense there could be volumes and volumes written about each of the subjects in her individual chapters.



The author intersperses conversations and bits of interview material within the text, and begins each chapter with a beautiful and insightful quote from the Indian poet, Tagore. The book leaves us wondering how much longer this study went on, if it is still active in this hospital, and if other hospitals offer the same kind of courses, or if the hospice movement, which resulted from this work, has replaced this kind of "seminar" format. Written in 1969, the book definitely feels dated, but its value in its field is indisputable.

Quotes

"What happens in a society that puts more emphasis on IQ and class standing than on simple matters of tact, sensitivity, perceptiveness, and good taste in the management of the suffering?" p. 9.

"Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending death which is so frightening and discomfoting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being which would remind us once more of our lack of omnipotence, our own limits and failures, and last but not least, perhaps our own mortality?" p. 9.

"If we are no longer rewarded in heaven for our suffering, then suffering becomes purposeless in itself," p. 15.

"Two years after the creation of this seminar, it became an accredited course for the medical school and the theological seminary. It is also attended by many visiting physicians, by nurses and nurses' aids, orderlies, social workers, priests and rabbis, by inhalation therapists and occupational therapists, but only rarely by faculty members of our own hospital," p. 27.

"Most if not all of the patients know anyway. They sense it by the changed attention, by the new and different approach that people take to them, by the lowering of voices or avoidance of sounds, by the tearful face of a relative or an ominous, unsmiling member of the family who cannot hide his true feelings," p. 36.

"Maybe we too would be angry if all our life activities were interrupted so prematurely; if all the buildings we started were to go unfinished, to be completed by someone else, if we had put some hard-earned money aside to enjoy a few years of rest and enjoyment, for travel and pursuing hobbies, only to be confronted with the fact that "this is not for me." What else would we do with our anger, but let it out on the people who are most likely to enjoy all those things? People who rush busily around only to remind us we cannot stand on our own two feet anymore. People who order unpleasant tests and prolonged hospitalization with all its limitations, restrictions and costs, while at the end of the day they can go home and enjoy life," p. 51.

"It would be contraindicated to tell him not to be sad, since all of us are tremendously sad when we lose one beloved person. The patient is in the process of losing everything and everybody he loves. If he is allowed to express his sorrow he will find a final acceptance much easier, and he will be grateful to those who can sit with him during this state of depression without constantly telling him not to be sad," p. 87.

"Acceptance should be not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain had gone, the struggle is over, and there comes a time for 'the final rest before the long journey' as one patient phrased it," p. 113.



"It [acceptance stage] is perhaps best compared with what Bettelheim describes about early infancy: 'Indeed it was an age when nothing was asked of us and all that we wanted was given. Psychoanalysis views earliest infancy as a time of passivity, an age of primary narcissism when we experience the self as being all.'" p. 120.

"And so, maybe at the end of our days, when we have worked and given, enjoyed ourselves and suffered, we are going back to the stage that we started out with and the circle of life is closed," p. 120.

"So then I said, killing myself is out because I'm too yellow to kill myself. That eliminates one possibility that I don't have to think about. I finally rid my mind of encumbrances as I go on, so that I have less and less and less to think about. So I eliminated the idea of killing myself by the process of eliminating death. Then I reached the conclusion that, well you're here now. Now you can either turn your face to the wall or you can cry. Or you can try to get whatever little fun and pleasure out of life you can, considering your condition," p. 151.

"Some relatives would be of greater service to the patient and the staff if they would visit less often and less long," p. 167.

"When anger, resentment and guilt can be worked through, the family will then go through a phase of preparatory grief, just as the dying person does," p. 169.

"I remember the mother of a young man in Colorado who did not allow her son to take any exercise, not even the most minimal kind, in spite of the contrary advice on part of his doctors. In conversations this mother would often make statements like 'if he does too much he will drop dead on me,' as if she expected a hostile act on the part of her son to be committed against her. She was totally unaware of her own hostility even after sharing with us some of her resentment for having 'such a weak son,' whom she very often associated with her ineffective and unsuccessful husband," p. 173.

"Was it Montaigne who said that death is just a moment when dying ends?" p. 268.



Topics for Discussion

What support is available for terminally ill patients today? What changes have taken place in this area since 1969?

Is Elisabeth Kubler-Ross a compassionate person? What is her goal in educating people about death and dying?

Discuss Kubler-Ross's five stages of grief and dying. Do these always hold true? Can we accurately compartmentalize grief in this way?

Discuss the attitudes toward death described by Kubler-Ross when this study began. Have they changed over time, and why? What is the evidence?

Why did doctors refrain from telling patients of the terminal nature of their diagnoses?

Who is Tagore, and why does Kubler-Ross use his poetry to begin each chapter?

Discuss your own death from terminal illness, and what you would like your doctors, hospital staff and relatives to remember.

Based on the interviews in this book, were religious people more likely to die peacefully? Why, or why not?

What are some of the issues that keep people from dying when their time is obviously past due?

Discuss why it is so difficult for human beings to accept the concept of their own death.