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Counseling the dying person

Claudia Vidano

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COUNSELING THE DYING PERSON

A Project
Presented to the
Faculty of
California State College
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
in
Psychology

by
Claudia Vidano
June 1979
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Chairperson
Date

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INTRODUCTION

I have what could be called a fear of death; more accurately, it is fear of an inappropriate death. And why shouldn't I rage at an unchosen death? Why shouldn't I decide how and when to die? And if I can't choose my way of death, it seems fitting to live in such a way that I will accept death whenever it comes. As Koestenbaum (1976) says, "The point is that we all realize that death is inevitable, yet no one wants to talk about it, face it, or do anything about it." (p. 1).

Well, I want to do something about it. I want to know about death, I want to know what part a person may play in her own death, consciously or unconsciously. I want to be reassured that my compelling need to understand death is a healthy drive to find meaning and purpose in life. If one can solve the problem of why death?, why will it happen to me?, how will it be for me?, then one can get on with the business of living.

As part of my search for answers to these questions, and to discover whether I could be of service to a person who is dying, a year ago I sought and gained membership in Caritas; an organization in Riverside which provides
volunteer counseling service for patients and families facing life-threatening illnesses. I have learned much during this year, and am still learning -- about facing death, about fighting a terminal illness, about the interrelationship of life and death. The purpose of this writing is to share this learning, and the learning process.

I'll begin by presenting some background on Caritas, how it started, what its aims are. Next, I'll describe some elements of the training I received after I was accepted as a counselor with Caritas. From there I'll talk about my counseling experience from several perspectives. Next is a short section on integrating the material and then some final conclusions.

Even though I will focus mostly on counseling issues, underlying my counseling experience and intimately connected with it is my search for meaning to life and death, and for guides in dealing with the realities of my human existence. So I have sought, on various intellectual, personal, emotional, empathic, and philosophical levels, to be open to the idea of death and the reality of dying individuals. I would like to encourage the readers to find in what I have written whatever may be of use to them in seeking their own personal answers, and questions, about death's meaning in their lives. Again Koestenbaum (1976)
expresses my feelings, "We must make certain that in these reflections on death we do not escape the issue of death -- by treating that sensitive topic as if it were a bacterial specimen under a microscope and not a disease gnawing at the very brain that is looking through the microscope."

(p. 19).
BACKGROUND

Before I go into my experiences with Caritas, I'll explain how it started and describe its functions. Helen Miller, R.N., program director of the Riverside Chapter of the American Cancer Society, through her work with the Cancer Society and her experience in clinical nursing, saw personal counseling as the greatest unmet service need for cancer patients and their families. She had read about Shanti, a project formed in Berkeley to provide counseling for the dying. Helen asked the Extension Office of the University of California at Riverside to bring Charles Garfield, founder of Shanti, to Riverside for a workshop. The workshop was held in late 1976.

Judy Giberson, an R.N. working at a local hospital, had called the Cancer Society earlier in 1976 seeking help for a friend of hers who was dying of cancer. After Judy and Helen talked about help for Judy's friend, they also talked about mutual concerns they had for certain services for the dying. Judy decided to help by becoming a volunteer counselor for the Cancer Society, and at the time of Garfield's workshop she was already counseling dying persons. Judy and Helen both attended the workshop and discussed the Berkeley project with Garfield.
Soon after that Jeanne Brown, of the Ministry of Caring of the First United Methodist Church of Riverside, called Helen to ask her to speak on death and dying for a meeting of the church group. The Ministry of Caring was involved with visiting the sick and saw the need for help for the dying. When Helen spoke at that meeting she talked about Shanti. The group was enthusiastic about starting a service in Riverside similar to the Shanti project in Berkeley. An organizational meeting was called in January, 1977, attended by Helen, Judy, members of the Ministry of Caring, and other people from the community who were interested.

After the organizational meeting, weekly meetings were held and Caritas, which means "the love that binds together all people of good will", was formed with funds from donations. Caritas used the Shanti Project as its model.

Shanti, a Sanskrit word that is equivalent to "the peace that surpasses understanding", was chosen as the name for the project formed to provide a way of meeting the psychological needs of the dying in the Bay area. Charles Garfield, Ph.D. (Psychology), and some colleagues recognized the need for a service for the dying, and Stewart Brand, who developed the Whole Earth Catalog, provided the suggestion that the best way to provide such a service was simply to organize a group of volunteers with
the time, interest and ability to work with the dying. The
volunteers would be reached through one central telephone
number, and would go out into the community, to homes,
hospitals, nursing homes, or any agreed upon location, to
visit patients in need of the service.

Shanti thus began in February, 1975, with a telephone
answering machine and a group of fourteen volunteers.
Their stated aims were "(1) to offer direct community
services, consisting of counseling and companionship for
patients and families facing life-threatening illness and
grief counseling for survivors of a death; (2) to provide
opportunities for professional training and public
education on relevant issues that arise in ministering to
the psychological and social needs of the dying and their
families; and (3) to conduct substantive research, using
research methodology from clinical and social psychology
and sociology, in order to evaluate the impact of the
Shanti Project as a community service." (Garfield and
Clark, 1976, p. 2).

Shanti now has more than eighty volunteers, provides
about 600 hours of free client counseling per week, serves
most of the San Francisco Bay area, co-sponsored the first
nationwide training program for counselors of the dying in
December, 1975, developed a statewide conference for nurses
on psychosocial care of the dying, participated in the
development of the first national conference for physicians on doctor-patient relationships in terminal illness, and has taught courses on dying for nurses and graduate students in psychology.

Caritas operates its counseling service the same way that Shanti does. There is a telephone answering machine in the home of Judy Giberson, Coordinator for Caritas. Judy answers all calls, some of which come from other helpers of the dying who are seeking information, some from those interested in joining Caritas, and the majority from patients, their family members, or friends. Though some people call because they feel their friend or relative could use the services of Caritas, Caritas will only counsel a person who directly requests help, or if unable to call, asks another to call Caritas for her or him. Judy has found that those who call seeking help for their friend or relative are often in need of someone to talk to themselves and she provides a form of crisis counseling to these callers. For relatives needing further counseling and for patients requesting help, Judy seeks a match with an available counselor, and the counselor begins visits with the counselee (a term chosen by Caritas to replace the terms patient and client). All counseling is free.

Caritas' stated purpose is also modeled after the Shanti Project's, but does not include research goals.
"The specific and primary purposes are to coordinate, train, and supervise volunteers who provide caring, counseling, and emotional support for individuals facing life threatening illness and their families, to provide continuing support for families in bereavement, and to provide informational services to the general public concerning grief counseling." (Articles of Incorporation of Riverside Community Caritas, Inc., 1979, p. 1).

In addition to the counseling members of Caritas, there are also supporting members, persons who contribute in an advisory or financial capacity, or in any other manner except counseling. Some of the advisory members include physicians, a lawyer, a rabbi, a minister, a priest, and a nursing home administrator. Though most of the original counseling members belonged to a church group, Caritas has no religious affiliation.

Volunteer counselors for Caritas are chosen by the same procedure developed by Shanti. Prospective counselors submit applications stating their reasons for wishing to work with the dying, their willingness to make at least a year's commitment, their personal experience with death and grief, and their background, experience, and interests. A screening committee of other counselors interviews the applicants who, if accepted, join Caritas for a three month probationary period which includes training.
The Shanti Project developed some guidelines for effective counselors.

In addition to an evident sense of compassion, we look for many other qualities, among them a high tolerance for role ambiguity; an ease in talking about dying (as evidenced by the degree to which that talking is personalized as opposed to merely philosophical); a high degree of introspection and self-knowledge; a healthy sense of self-confidence; a high tolerance for frustration; a degree of psychological mindedness; a sense of humility that allows one to view sharing in someone else's dying as a joint process with learning occurring on both sides; the ability to speak and to understand metaphor, whether religious, cultural, or symbolic; and relevant professional training in counseling, psychology, social welfare, nursing, or medicine. ...factors that would exclude a prospective volunteer from the Project are a powerful need to be controlling and a strong belief that there is a "right way to die." (Garfield and Clark, 1976, pp. 9-10).

Caritas uses similar guidelines. The group stresses to prospective counselors the need for confidentiality, does not accept someone whose religious background includes a need to convert, is cautious about those whose own needs are so strong that they may develop an unhelpful over-involvement with the counselee, and requires, above all, that the prospective counselor be a caring person.

At present, there are about twenty Caritas counselors, ranging in from 22 to 87. There are nurses, housewives, counselors, students, social workers, a massage therapist, and others. Religious convictions of the members range from strong to none. Many members have personal experience with death of a close family member.
In April, 1978, I was accepted into Caritas as a probationary counseling member. I have completed my first year's commitment to the group and will continue with Caritas as a counselor for at least another year.
TRAINING

Each new probationary counseling member of Caritas goes through training. As stated in the Standing Rules, the training period shall be 6 to 8 weeks one night a week. Training shall consist of discussion of stages of dying, stages of grieving, and other written material, Elisabeth Kubler-Ross tapes and ACS tapes, role playing, death awareness discussions and sharing. (Riverside Community Caritas, Inc., Standing Rules, 1979).

I began my training in May, 1978. Helen Miller, president of Caritas, conducted the sessions for our group of three -- myself, another woman, and a young man. We began by getting acquainted with each other, primarily sharing our separate experiences of death and dying up to that point. Each of us had been through profound losses, and we talked about what we had learned from our grief experiences, what we felt would have helped us at the time, what we had learned about dying from losing a close relative through death.

Helen, who had also related her personal experiences, then proceeded to cover the material on death and dying that was considered most relevant and useful to the type of work we would encounter as Caritas counselors. We stopped
whenever necessary to discuss points in more detail, or to question certain ideas. We met and continued in this manner for two to three hours one evening a week for six weeks.

Kubler-Ross' Stages of Dying

A substantial part of what we covered in our training was based on the work of Elisabeth Kubler-Ross, and the stages of dying that she delineated (1969). Since her name so frequently arises in any discussion on death and dying, and since so much has been written concerning her stages of dying, I think it would be appropriate at this point to examine what she and others have to say about her five stages of dying.

The first stage is shock and denial, the "No, not me!" stage. Then comes the stage of rage and anger, the "Why me?" stage, followed by the bargaining stage -- "Yes me, but..." The fourth stage is depression, initially reactive depression or mourning past losses, then preparatory depression, preparing for impending losses. The final stage is peace and acceptance.

These five stages have been widely discussed and sometimes criticized. I think that often the notion of the stages are referred to as theoretical concepts without taking into considerations that Kubler-Ross speaks of these
stages as aids to understanding, being with and helping a
dying person. She does not just present the stages as,
"This is what the dying person goes through,"; rather,
she says, "This is a certain stage of dying. Here is what
is important about this stage, and here are some suggestions
for recognizing the stage, and being with the person during
this stage." She does not present the theoretical without
the personal and immediate. Also, she did not develop the
theoretical and then go out and attempt to apply it. She
learned from the dying people she worked with, and her
stages reflect what she felt was a way to write about what
she had learned from them.

Let's examine in more detail what Kubler-Ross has to
say about these stages. The first stage, denial, is used
by practically all patients at some point in their illness.
Usually there is an initial reaction that "this can happen
to others, but it cannot happen to me." After the initial
denial, some patients go on to other stages, some need to
return to at least partial denial from time to time and some
need denial until the end, never moving out of this stage
because the reality of their life situation is too difficult
for them to bear. Sometimes family members or others
helping the dying person are experiencing the denial
themselves. The dying person senses that others do not
want to confront her death, and so she does not talk about
it. This is not really denial, and if she knows there is at least one human being she can talk openly with, she will, according to Kubler-Ross, drop the seeming denial.

When the helpers or family members are certain that the denial is not their problem, but that of the patient, then the helpers or relatives can convey a willingness to listen whenever the patient might want to talk. At all times it is important to respect the patient's need for denial, take cues from the patient, consider that she may talk about her illness symbolically. Any conversation must be at the convenience of the dying person, not the listener, with the understanding that the topic will be terminated when the patient indicates an unwillingness to continue, perhaps by again denying the seriousness of the illness.

The second stage, anger, is often difficult for those close to the dying person to cope with. This stage occurs when the feelings "No, it can't happen to me" are replaced by "Yes, it is happening to me," and then the question, "Why me?" When denial is absent and awareness sets in, feelings of anger, rage, envy, and resentment are likely to surface. The patient may feel angry about the treatment, may feel bitterness and anger toward the doctor, or resentment toward any other healthy person, or family member. The worst way to handle overt anger or rage, according to Kubler-Ross, is to try to dampen it with
kindness. It is preferable to assure the person that she has every right to be angry. Further, she should be allowed to express her anger, and to get out her rage and resentment. This self expression helps the patient to move toward the final stage of acceptance, rather than perhaps becoming ungrateful, nasty, critical, and continuing that way until death.

Some dying persons may have less overt anger, and can be encouraged to express, can be given permission to vent, their anger. Others may have long standing anger or resentment in their lives that was never expressed and is now confused with the anger over their current illness. Kubler-Ross goes into detail about one patient, a young nun with Hodgin's disease who was an angry, demanding patient who aroused much resentment in those who had to care for her. Kubler-Ross reprints an entire interview with the nun in order to show the great need this nun had, stemming from anger and resentment that originated in her childhood. The interview illustrated the positive changes that can occur when a patient is allowed to be herself, which in this case meant the helper's allowing the patient to be hostile and demanding without the helper's taking the anger personally, and without judging the patient. The nun was able to ventilate her rage, relieve the burden of some of her past life, and reveal the side of her that was capable of warmth,
love, insight and affection. With continued visits, the woman's behavior changed considerably and the attitude of the hospital staff also changed to one of more understanding.

I found one part of the story of this nun particularly instructive, not about anger, but about being dedicated to the needs of the patient. The nun had asked Kubler-Ross to read to her from the Bible. Kubler-Ross says,

I did not enjoy this assignment as I found it somewhat peculiar and beyond the usual things I was asked to do. I would have felt much more comfortable had she asked me to give her a backrub, empty a nightstool, or something like that. I also remembered, however, that I had told her we would attempt to fulfill needs, and it seemed somewhat cheap to call the hospital chaplain when her need seemed urgent at that very moment. I recall the dreaded thought that some of my colleagues might come in and laugh at my new role, and I was relieved that nobody entered her room during this "session". (1969, p. 80).

I am making a comment here more about Kubler-Ross as a person, rather than about her theories, by including the above quote. I believe it shows her willingness to be transparent and personal, and knowing how she coped with certain incidents with patients is every bit as helpful as whatever value her stages of dying may have in terms of working with a dying person.

One of the last sentences in her chapter on anger is about this same nun and illustrates again how she learned from the patients. "Many of us still remember her, not for
the difficulties she had caused, but for the lessons she had taught many of us." (Kubler-Ross, 1969, p. 81).

An additional point about the stage of anger is for those who work with or are close to a dying person to realize that sometimes that person's anger is a completely justified, righteous anger in response to something in the environment. Sometimes the person is angry not because of the general condition of having a terminal illness, or because of unresolved problems in her or his life before the illness, but because they are being treated unfairly or uncaringly. Kubler-Ross cites the example of a man paralyzed from the neck down, who did not wish to have the siderails on his bed put up as it reminded him of being in a casket. A nurse expressly went against his wishes and he was furious, as he certainly had a right to be. Kubler-Ross analyzes the incident by taking into account the nurse's uncomfortableness in caring for this terminally ill man, her need to have him be still and make no demands on her (he asked if he could be put in an upright position, and she responded by putting up the siderails, claiming it was necessary) and her destructive wishes that he die, which came out in a confrontation between the nurse and the patient which Kubler-Ross witnessed. After citing this example, she stresses the importance of always listening to the patient's anger, whether it is rational or
irrational. She says,

Needless to say, we can do this only if we are not afraid and therefore not so defensive. We have to learn to listen to our patients and at times even to accept some irrational anger, knowing that the relief in expressing it will help them toward a better acceptance of the final hours. We can do this only when we have faced our own fears of death, our own destructive wishes, and have become aware of our own defenses which may interfere with our patient care. (Kubler-Ross, 1969, p. 54).

The third stage, bargaining, could also be seen as a "Why now?" stage. In this stage the person attempts to postpone the inevitable. Often the bargains are with God, with patients promising a life dedicated to God in exchange for more time. This is probably the least talked about stage, in terms of references to it in the literature. It is not clear whether Kubler-Ross considers this stage as important as the others, and whether she feels most patients go through it. She devotes very little space to it and I get the feeling that it is a stage that only some, and maybe just a few, go through.

Reactive depression and preparatory depression constitute the fourth stage of depression. Reactive depression is the reaction to losses already suffered, such as the man who still mourned the deaths of his parents and daughter, or the woman with uterine cancer who mourns the loss of her childbearing function. The reaction to the general loss of one's health and roles in life are also
part of a terminally ill person's depression that Kubler-Ross calls reactive.

The type of depression that takes into account impending loss, rather than past or present loss, is called preparatory depression. Kubler-Ross has also called this stage preparatory grief, a term that fits better for me. In this stage persons mourn future losses, their own death, loss of all the people and things that have meaning to their lives. They don't talk much in this stage and it is inappropriate to help them change their attitude, as it might be in reactive depression. In preparatory grief or depression, it is important to sit silently with the person. Not to allow this stage would be not to allow the person to contemplate her or his impending death. During this stage the person feels little need for words, and so does not want too much interference or distraction from visitors. This stage is very hard for families. When a person is lying quietly with tears rolling down his cheeks, it is often difficult for others to deal with. The person must be allowed to grieve, to cry, to express sorrow, and to shed tears.

During preparatory depression or grief, the patient's needs are more simple for the helper of the dying person to deal with, if the helper can allow, and not interfere with, the silent sorrow. But the family may need a lot of
support at this time, since they feel the person withdrawing from them. A sensitive helper will want to assist the family in working out their feelings at this time, and to the extent that the family can understand and accept this stage, their grief work will be lessened after the person's death.

During the final stage, acceptance, the person has finished unfinished business, is no longer depressed or angry about the illness. At this stage hope is no longer associated with cure, treatment or prolongation of life. There is inner and outer peace, a stage of "the final rest before the long journey." (Kubler-Ross, 1969, p. 113). Kubler-Ross found that people who come to the stage of acceptance more easily are usually older, content with the accomplishments of their lives, have found meaning in life, and feel that the end is near. Others may have to struggle through the previous stages, expressing rage, crying in preparatory grief, expressing their fears and resentments to someone willing to listen in order to reach the stage of acceptance. Given enough time to prepare, Kubler-Ross feels that most patients will reach the stage of acceptance, of victory and peace. She compares this stage to Bettelheim's description of 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.

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. (Kubler-Ross, 1969, p. 120).

Alternative Views of Stages of Dying

Much of the literature disputes that there are actual stages of dying. Weisman (1974) does not feel that going through stages is the same as the process of dying. He states that patients seldom conform in all ways to the staging procedure, and that trying to describe and define events surrounding dying by using the concept of stages is to lapse into the magic of naming. Naming, he says, is a way of getting control over something, and he prefers to think of dying in terms of process.

In a case conference attended by Weisman, who is a medical doctor, and by other doctors, a psychologist, and a social worker, the subject of stages was discussed. Two doctors felt that in the cases they knew, the patients did not go through all the stages, and did not go through stages in a particular order. The psychologist noted one patient whose denial was not limited to his illness, but was related to other aspects of his life as well. I liked Weisman's practical approach of discussing the stages with a view to actual cases, and not just from a theoretical perspective. He concluded that while the idea of stages is
appealing to him, and though he believes that patients have certain strategies for coping, "that there is no well-recognized succession of emotional responses which are typical of people facing incipient death." (Weisman, 1974, p. 96).

Garfield (1976) would agree with Weisman's statement. He makes a strong point that there is no empirical evidence from researchers or practitioners identifying "preprogrammed ... linear, unidirectional and invariant stages... in the dying process." (p. 1). He does not think that all people, regardless of other factors such as age, race, culture, historical period and belief system will die in a similar fashion. Garfield cautions against these misassumptions concerning stages, and cites personal experience with nurses trying to force patients into the next appropriate stage, afraid to let them die until they have worked through each stage and reached acceptance. He views denial, anger, depression, and acceptance as reactions to dealing with death, not stages of dying, and examines the ways in which physicians as well as patients, exhibit these reactions.

Drawing on his own work with the dying, Shneidman (1976) has seen isolation (a component of denial), envy (a component of anger), bargaining, depression and acceptance in the dying person, but does not believe these are necessarily stages of the process of dying, or that they are lived through in
any order. He sees a clustering of intellectual and affective states, lasting from a moment to days or weeks, and always occurring in the context of the person's personality and attitude toward life. Rather than stages, he posits

a hive of affect...a constant interplay between disbelief and hope and, against these as background, a waxing and waning of anguish, terror, acquiescence and surrender, rage and envy, disinterest and ennui, pretense, taunting and daring and even yearning for death. (Shneidman, 1976, p. 447).

He also sees an ongoing alternation between the phenomena of acceptance and denial, between knowing what is happening and needing not to believe reality.

Leviton (1977) notes that even though Kubler-Ross explicitly wrote that her concept of stages ought to be tested, many in the field of thanatology accept the stages as gospel. He cites a review of research on the process of dying by Schultz and Aderman (1974), who reported that most researchers did not find that dying occurred in stages, although there was agreement that terminal patients are depressed shortly before they die, which concurs with Kubler-Ross' notion of preparatory depression or grief that occurs before acceptance. Leviton suggested that researchers and educators regard any stages as unproven for now and simply theoretical.

None of these authors really contradict Kubler-Ross' work as I understand it. Actually, I think many who write
about the stages have looked at the idea very narrowly or are reacting to the way others have misunderstood the idea, and have neglected to sense the whole of Kubler-Ross' concepts. Nevertheless, all the discussion generated by her notion of stages has been useful to anyone in the field of thanatology, showing the importance of a careful examination of any concepts, even those of such a charismatic and central authority in the field as Elisabeth Kubler-Ross.

The important points in the literature on stages of dying, and those stressed in our Caritas training, can be briefly summarized. A person who is dying may manifest certain emotional states such as anger, depression, acceptance, or denial, and perhaps less often, bargaining. It is important to recognize that these emotions can be a response to the illness or impending death and can also be a reaction to other life situations. There are guides in the literature for giving helpful responses to a person who can be recognized as exhibiting signs of one of the "stages". A patient should not be made to conform to a model of dying. Rather, a patient's behavior should be observed and a model of caring for her or him developed from being with, listening to, and learning from her or him, as well as drawing on relevant theoretical formulations.
Pattison (1976) says it very well.

I find no evidence...to support specific stages of dying. Rather, dying persons demonstrate a wide variety of emotions that ebb and flow throughout their living-dying...I suggest that our task is to determine the stress and crisis at a specific time, to respond to the emotions generated by that issue, and in essence respond to where the patient is at in his living-dying. We do not make the patient conform to our idealized concept of dying, but respond to the person's actual dying experience. (p. 82).

Death Awareness

While a lot of the background on death and dying that we were given in our training was based on the work of Kubler-Ross, there were other important elements of the training. One of these elements was the experiential understanding of our own relationship to death. We gained insights into our feelings about death through some death awareness exercises. For instance, we were asked to relate the three most significant changes that have occurred in our life.

If the reader of this paper is interested in experiencing some of the material along with just reading about it, I would encourage you to stop for a moment and think about or write about the three most significant changes in your own life.

Helen, who was conducting the training, had learned this exercise from Charles Garfield, founder of Shanti. According to Garfield the most significant changes are
usually losses. While this was not specifically true for me, I did note that all my changes involved a loss of who I had been and an evolving into someone a bit different, much like the loss of childhood at adolescence.

The point of the exercise is to experience insight into the presence of loss and change in our lives. To the extent that we realize the emotional impact on us of significant losses, we are more open to relating to the bereaved and dying. One of the trainees shared with us his responses to this exercise. A significant change was occurring in his life at that time. Two members of his immediate family had died within the previous year, and the only remaining family member, other than the trainee, was in the process of selling the family home. While the trainee had been aware that this change would be difficult for him, he had not been fully in touch with the traumatic emotional loss that the sale of the house represented. To him, the house was symbolic of his life and memories of life with those close to him who had so recently died. He was able to release his feelings of loss and sadness over this change. In sharing his feelings so openly with the rest of us, he helped us realize the impact of loss and change on our own lives, as well as experience how to be helpful and supportive to someone expressing loss.

Since many people go along in life not thinking about or expecting death, they are often not aware whether they
are really living their life the way that would have the most meaning for them. In order to recognize our personal values, and our ability or lack of ability to live our life congruent with these values, we reflected on our answers to these questions:

If I were to die tonight, would I consider my life has been complete?
What are three accomplishments of which I'm most proud, or three things that I like most about myself?
What are the three things that I regret the most in my life, or the three things that I would most like to change?

Again, I'd like to suggest that the reader might like to take some time to also reflect on these questions.

Another exercise we did, and which the reader could do, is to take a sheet of paper and write on the top, My Own Death. Then write whatever spontaneously comes to you. I would like to share mine since the writing of it and reflecting on it was important for showing me my notion of an appropriate death.

My Own Death -- Claudia

My own death will be peaceful. I will die without pain, just quietly die. I hope there will be loved ones
with me when I die. I want to die at home. I don't want
to die until after my children are at least in their
twenties.

On the surface, this seems a simple and maybe
stereotypical notion of death. But my spontaneous answers
actually surprised me, and I learned a great deal from the
exercise. Part of the surprise was the notion of dying
without pain, since I once experienced a near death after
an automobile accident, and there was a great deal of pain.
The interesting part of that death experience is that I
decided to die as the only way I knew to transcend the pain.
I actually experienced extraordinary peace at that moment of
decision, and I did transcend the pain. Two factors, however,
"saved" me. One was a thought I had that distracted me for
an instant from the decision to die. I thought about how
strange and unfortunate it would be for my husband to be
widowed at twenty-six. The other factor was that a thoracic
surgeon was inflating my collapsed lung, the source of the
all-encompassing pain from which I sought relief.

In writing My Own Death, I don't think I wrote "I will
die without pain" because I am afraid of pain. I think I
wrote that because my experience with almost dying taught me
that the moment of death is not painful. Perhaps that is
not true from any research point of view. I don't know.
It doesn't matter in this context, because for me I believe
that death will not be painful, since I know that extreme pain near the moment of death can be transcended.

The spontaneous thoughts that death happens peacefully at home surrounded by loved ones may reflect how I experienced the deaths of my brother and my father. Both died in this manner, and so I guess I expect to do the same. Both also died of fatal diseases, after some months of debilitating illness. I had to realize that my notion of my own death would seem to indicate advance notice that I was going to die. This awareness left me reflecting whether I indeed thought of death from disease as an appropriate death for me. A year later I am still reflecting on this.

I also had to consider how my notion of appropriate death would influence my work with the people I would counsel through Caritas. Since these people all have life threatening illnesses, would I want to somehow direct them toward the model of death fixed in my mind from being with my brother and father at the moment of their deaths? This was good to ponder and would remain unanswered for a time.

The last sentence on my own death was, "I don't want to die until after my children are at least in their twenties." This statement connected strongly to the answer I gave to a question mentioned above, "If I were to die tonight, would I consider my life has been complete?" The answer was no,
I would not consider my life complete. I saw then that one of the elements of incompleteness was not having fulfilled the role of raising children. At the time I wrote that, I had only one daughter, a child, not children, that I was raising. So again my answer surprised me, but made me realize that I did wish for more children. I have since become pregnant, so the statement was prophetic in a way.

Also, I believe that I wanted my children to be "at least" in their twenties because I was only sixteen when my brother died, and in my twenties when my father died. Though the loss of my father was in many ways more painful, I had a better grasp on a philosophy of life and death than when my brother died. I guess I do not wish for my children to have to suffer such a loss as I imagine my death would be to them, while still growing and learning about life. Also, my youngest brother was only fourteen when our father died, and a part of me just rebels that children must suffer in that way.

This has nothing to do with a "right way" to think about death, but it has everything to do with realizing some very personal reactions to death, which was the point of the exercises. There is great value in exploring one's personal reactions to death, and for someone seeking to be with or help a dying person, it is essential.
COUNSELING

Trends in Literature on Thanatological Counseling

In the past, management of the dying person usually has involved the patient's physician, nurses, family and clergy. Recently, the psychotherapist has begun to take a role, often filling the gap left by the rabbi, priest, or minister in an increasingly more secular society. Often for people in whom there is a vital need for the clergy, there is still a role for the psychotherapist since religious convictions, even including the belief in an afterlife, do not, as LeShan (1961, p. 319) says, "obviate the patient's need to explore himself and his relationships with others."

Leonard Pearson in 1969 published an annotated bibliography on death and dying. The section entitled "Psychotherapy with the Dying; Managing Death" lists 150 titles. The date of the earliest title listed is 1912, and the selection is called "Thanatology", published in the Journal of the American Medical Association, and according to Pearson's comments defines thanatology as the

study of death, its nature and its causes.
Among the questions investigated: when does death occur; what are the possibilities of
the dead body affording viable products for transplants into the living body? (Pearson, 1969, p. 174).

The article would hardly seem to address therapeutic issues, so it probably comes under Pearson's other heading, Managing Death. Still, it was a beginning in the field.

The date of the next title, chronologically, after the 1912 article, is 1940. There are only twelve titles dated in the 1940's, one an unpublished dissertation on "Tudor books of consolation" (Pearson, 1969, p. 172), another on "Fear of death" in Psychoanalytic Quarterly (Pearson, 1969, p. 180), and all the others from either a medical or pastoral perspective.

Thirty-four titles are listed as published in the 1950's. These are mostly religious (e.g., Ye Shall Be Comforted, Pearson, 1969, p. 177), or medical ("an English surgeon discusses his attitude toward death and his approach to it with his patients", Pearson, 1969, p. 174), but the medical viewpoint is taking on a new slant. Many of the titles are from the psychiatric and psychoanalytic point of view, and many aimed at others in the medical profession are geared toward "should the patient be told?"

There are 102 titles from 1960 to 1969, when the bibliography was published. In this decade, the medical field predominated, the religious was losing ground, and the psychological and psychotherapeutic began to take hold.
There was beginning to be a switch also from "should the patient be told?" to "how to tell the patient he has a terminal illness."

Since 1969, when not so incidentally, Kubler-Ross' enormously popular On Death and Dying was published, the field of thanatology and thanatological counseling has taken off from the slow trot of the forties and fifties to a gallop that threatens to be a stampede in the seventies. There are three points worth mentioning about this outpouring of literature. First, it is increasingly being addressed to the general population. Secondly, the predominant subject matter is no longer medical and religious, but psychological, philosophical and practical, such as

...how to deal with terminal illness, how to prepare oneself for death, how to cope with the loss of a loved one...what it actually means to die, how the fact of mortality shapes human living, how one might live with mature awareness of death's inevitability. (Loudon, 1966, p. 107).

The third point centers on the need to take a harsh and critical look at the meaning and value of all this contemporary interest in death. Steinfels (1974) cautions that the recent flourishing of literature on death may not necessarily be "healthy". He talks about the middle ages when death became the center of attention, reflected by the preoccupation with death of the preachers, poets, artists,
and writers of that society. But he points out that it was a society in decline,

...its obsession with death reflected the seeping away of its creative force, not the energy to construct a more livable and die-able world. Is it possible that the future historian of our time will decipher in our own sudden interest in death not an influx of wisdom but rather the cracking of our cultural nerves? (p. 3).

He feels that the real question that death poses concerns the meaning of life, and that this may be obscured by a trend toward what he calls "how-to-do-it-guides for the dying". He mentions recent titles such as Living Your Dying, Death Is All Right, and To Die With Style, and comments, "How long before some Joy of Dying ("A Gourmet Guide to Passing Away") makes the best-seller lists?" (p. 3).

Loudon (1977) feels that the discussion of death, which was supposed to have been a taboo in American culture, has now threatened to become "a light industry" ranking with "sex, cooking and movie stars as a staple of popular magazine fare." (p. 106). He continues,

Suffice it to say that there is now a great deal of talk about death. The seeming wall of silence has been breached at many points and fallen all at once, and the problem may be that all the chatter about death drowns out any serious confrontation with its real mystery. What was once wrapped in silence seems covered with talk. And whether the talk has made a real difference in people's lives--and deaths--is open to question. (p. 107).

Because it seems appropriate to the point Loudon is making, I'd like to include here a portion of an interview
I had with a cancer patient. I began the interview by a few remarks on how there was no longer a taboo on discussing death and dying, and before I could go any further, she interrupted me with,

"That's a fallacy, that death and dying and serious illness is no longer a taboo. The people where I live are elderly. I go to the pool and they ask, 'How are you?' and I say, 'It's just awful', and they look away. They want you to say, 'Just fine.' It's okay to talk about it until it gets personal. ...More and more people are turning away. They're old, they're going to go that way too, and they can't take it. Initially they're very sorry, but that wears off. I understand it, so it doesn't upset me...I wonder if you just don't face it alone with God. You long for the support and comfort of a loving human being, but you wonder how many could really be able to do that."

The type and amount of literature on counseling the dying person has changed over the last forty years, supposedly reflecting a new cultural openness about death. But when it comes down to an individual facing death, the changes of attitude intimated by the literature on death and dying may not be of any real value to the dying individual. To find out what is of value to a person with a life threatening illness the best source is the person herself. In the next section I'll discuss this issue.
Listening to the Patient

"Let me help you," said the monkey to the fish, as she put the fish safely up the tree.

After I finished my training period with Caritas, I began attending the group's regular meetings. A part of each Caritas meeting is devoted to "counselee reports", and at the first meeting I attended I listened with curiosity, professional objectivity, sadness, a little anxiety and awe while these ordinary people sat and talked about what suddenly seemed extraordinary -- counseling a dying person. What made the topic extraordinary was that each "report" was of actual people, actual deaths, actual terminal illnesses, actual grief and pain. Previously, I had heard a story now and then, I had had many discussions of death and dying, usually interspersed with personal accounts; in training we heard Helen give accounts of her work with counselees; I had read first hand accounts of dying. None of this was quite like sitting there and hearing person after person relate, simply and straightforwardly, matters of life and death. Each report was so real. I could not escape that the lives, the living and dying, that I was hearing about, were happening right now to real people. I felt privileged to be allowed to know the intimacies of the counselees' lives, and I was impressed by the manner in which the details were presented.
There was no false air of professionalism, no bantering of abstract theories, no objectifying the situation, no sense of "them" and "us" when referring to counselees. There was basically a sense of human caring, a genuine concern for how best to be with and help a particular person or family. There was a quality of humility, for lack of a better word, in these counselors. They didn't have all the answers, or even all the questions, but they all seemed to understand the importance of honest human contact with their counselees. I decided there were many professionals -- clinical psychologists, psychiatrists, counselors, social workers -- who could learn a lot from these people about authentic helping.

I wanted to take notes. I wanted to write down the details of the "cases". Being in this group was my project so I should be recording any useful information. But being in this group was more than just a project. I had been drawn here by a series of events on my search for the meaning of death, and more importantly, I had joined this group because I thought that the next step for me was to help others with problems of death and dying. I realized at that first meeting that attitudes of detachment, apartness, objectifying were not going to be helpful if I was to learn what this group had to teach me.
I took no notes. Somehow to do so seemed an invasion of the privacy of the counselees. And to write anything down was also to miss the full impact of what the counselors were saying. So I just listened and kept my heart and mind and the wholeness of myself as open as possible to the experience. I continued feeling this way at the meetings for some time. Now I am more accustomed as to what to expect at meetings and I definitely make notes to myself on points I want to remember. I try now to integrate the feeling and thinking aspects of my self, the emotional and the cerebral. And I am still learning what was so apparent at that first meeting, that to help someone you must not think you know what is best for them, you must listen to them and learn from them.

There are many examples in the literature of the importance of listening to and learning from the patient. Steele (1977) says, "In most situations, it is important and sufficient to be with the bereaved or dying person, listening to their concerns and supporting them." (p. 166).

This is a typical comment of those who work with the dying. (Davidson, 1978; Kavanaugh, 1972; Saunders, 1969; Krant, 1974; Pattison, 1976). LeShan (1969) has written extensively about working with patients with a limited life span. His approach will be discussed more fully later, but I'd like to include some of his comments in this section.
Ultimate concern means primacy; other concerns—in this context, the therapist's concern for himself and his own ego, for his hurt if the patient dies, for his pride and his persona—must be secondary and sometimes sacrificed.

...this type of therapy...needs intense concentration, almost absolute caring and acceptance...Basic is insistence on a real encounter, a real contact between the patient and the therapist. (p. 850).

A very good example of a true encounter with the patient's thoughts and feelings is given by Garfield (1976). A hospitalized woman had for many months been seen as a difficult patient by the staff. She seemed belligerent, demanding, and unresponsive to efforts by the staff to help her. However, no one had thought to ask how she felt, what kind of treatment she wanted. So Garfield suggested to the staff that the woman be included as a colleague and allowed to speak about what was the best treatment for her. The woman, upon being presented with the plan commented, "Now, that's the first sensible thing I've heard since I got here." (p. 14). Naturally, after the staff listened to her suggestions the situation improved remarkably.

A comment by one of the patients interviewed by Kubler-Ross (1969) is instructive on this point. "And all the kind people that pushed that wheelchair just drove me to distraction because they pushed me to where they wanted me to go, not where I wanted to go." (p. 70).

There are different levels of being able to listen to the patient, understanding her or his true needs. Sometimes
it will involve just holding a person's hand; sometimes, as in the example with Garfield, it will involve being an advocate for the patient with others who are involved with that person's treatment. In my experience, the important point to remember is that the person knows more about her needs than anyone else, so it makes sense to take the cues from the patient in helping her.

A situation that arises with Caritas counselors is truly being with a counselee when she is trying to make a decision to end treatment, usually radiation or chemotherapy. These treatments have many unpleasant side effects. Nausea, vomiting, diarrhea, constipation, weakness, lethargy in moving muscles, tingling or burning sensations in the hands and feet, loss of hair, bruising and a variety of skin rashes are all possible physical effects of treatment. One of my counselees also made me aware of the psychological effects, in this case, of radiation therapy. She commented that having to go every day, to spend a good deal of time and usually all of one's available energy for the day just to keep the appointments, to lie on the table, alone, with thoughts of the powerfulness of the treatment, is to be constantly reminded of the disease when the person may feel well enough to be doing other things with her life. The anguish of sacrificing so much of whatever time may be left can be quite great, and being forced to consider the
disease daily can be most distressing, aside from any negative physical effects.

Often our counselors are torn, if after a year of seeing a person, she decides to stop treatment. While realizing that our role is to be supportive, to be a patient advocate, to listen to the person's expressed needs, when a counselor has her own feelings of hope that the person may be cured, or brought into remission by treatment, it can be very difficult to be supportive of the person's desire to quit treatment.

Sometimes it is not as difficult. I had a counselee who was having such severe reactions to chemotherapy that I was relieved when she decided to stop treatment, and in that case, when she asked for my advice in making the decision, I had to be very careful not to err on the side of overly encouraging her, until it was clear that this was what she really wanted to do.

I'd like to end this section by once again emphasizing that the foundation of what we do in Caritas is to simply "be there" for the counselee. All else follows from that premise, and without the ability to be concerned first of all with what the person needs, anything else is of little value.

The following is a first person account by a forty-three year old man. It was written three months before he
died of leukemia.

Soon after I found out that I was in the acute stage of the leukemia, a friend came in and sat down. I was just right on the verge of tears. I had no way to deal with my feelings... and I could not speak. I said to the friend, "Hold my hand," and we just sat there. After a while my friend said, "Would it help to talk?" I said, "No, not now," and we just sat there quietly for at least an hour. Later my minister came and I was able to talk, but the person who just sat with me was most helpful when I needed that kind of care. The same was true when I was treated with the... chemotherapy and I reacted to it so very strongly with deep, heavy nausea... A friend came in, and I was able to open my eyes and see that she was there. She sat on the edge of the bed and took my hand and I could sense her weeping, but all I could do was say, "Thanks for your tears and thanks for being here." And that was it... but just the person's presence and her being there was helpful. Being present is very important. (Gattis, 1977, p. 137).

Types of Patients

While all persons have individual needs, including those with a terminal, or life threatening illness, I'd like to suggest that counseling styles and approaches will vary most according to the phase of the person's illness. In other words, time intervals and physiological states will provide more information for setting counseling guidelines than distinguishing people by personality types or psychological labels. It seems reasonable that it will be quite different to "be" with a person on her deathbed than to be with a person who, though diagnosed as having a limited life span, is leading an active life.
Weisman (1974) makes an extensive analysis of stages of dying, not psychological, but based on changes in anatomical and clinical status. The first stage he calls prediagnostic and diagnostic, which begins when the person first suspects disease and ends when a diagnosis is given. During this stage a person may delay finding out about the illness, may deny that the symptoms could be serious, or may seek medical attention immediately.

Stage 2 is the time of established disease. The person at this time is under at least periodic medical care for her disease. This stage includes primary treatment, such as surgery, radiation, or chemotherapy, aimed at cure, palliation (easing of symptoms without expectation of cure), or rehabilitation. There are various possibilities for outcomes during this stage, such as remission, relapse or recurrence, and decision to end treatments or begin secondary treatments.

In Stage 3 the person begins to decline and deteriorate. There is no sharp line to distinguish when Stage 3 has begun, especially since some people seem to decline only to make surprising recoveries. This stage represents a period of observable physical, physiological and behavioral changes, and is the terminal stage, the stage when death is now expected. Weisman says an even simpler staging process is to say a patient "is first sick, then becomes sicker, then
very sick, and finally the sickest of all." (Weisman, 1974, p. 47).

Pattison (1976) concurs with Weisman's analysis and suggests three phases of dying, the acute crisis phase, the chronic living-dying phase, and the terminal phase. Dealing with a person in the first phase is best seen as crisis intervention. Pattison suggests there will be acute anxiety at the knowledge of impending death, which will reach a peak, when the person must use whatever available psychological coping mechanisms s/he has to face the crisis. If effective mechanisms are not available, the person will begin a disintegrative dying style. Pathological defenses are not surprising in this phase, but the focus should be on emotional support and reality issues as the best way to reduce anxiety.

During the second phase, the chronic living-dying phase, the person faces many fears that must be dealt with appropriately as each arises so that the successful resolution of them will enhance the person's self-esteem, dignity, and integrity. The fears that Pattison explores are fear of the unknown, of loneliness, or sorrow, of loss of body, of loss of self-control, of suffering and pain, of loss of identity, and of regression. Pattison elaborates on these fears and suggests guides for successful resolution of them.
Pattison's third phase, the terminal phase, like Weisman's stage of decline, has no precise onset, but begins about when the person begins a physical withdrawal into himself in response to bodily cues, much like a person with a bad case of flu loses interest in everything except being left alone to curl up in a warm bed. The best help to be given during this phase is support for achieving separation and withdrawal.

The distinction between types of patients according to the physical phase of their diseases is useful to me in conceptualizing my experience with terminally ill persons. So far in my work with Caritas, I have not had to deal with the death of a counselee, or even deal with a counselee in the terminal phase of disease. So in terms of this project the dying people that I see are very much alive. Accordingly, I will restrict most of my comments in the following section on psychotherapy to issues of working with people in phase 1, acute crisis, and especially phase 2, the chronic living-dying phase.

Psychotherapy Issues

In this section I want to focus mainly on my first hand experience, so I will not be discussing direct counseling with those in end-stage or the terminal phase of disease. I'd like to share some of the problems and concerns I've struggled with in this year of counseling.
The most striking feature of the counselees I work with is that they are living, not dying. Aren't we all dying? The only difference, and it's by no means a small one, between them and me is that they have a disease which is likely to be the cause of their deaths in a few years or months. Nevertheless, they are living, look as healthy as I do, and have problems of living as well as of dying.

Their dying cannot be ignored, however. To ignore their disease and prognosis so as to focus just on issues of living would be engaging in what Kalish (1977) calls the "horse on the dining room table" syndrome. (p. 226). Guests and host are seated for dinner and it is noticed by everyone that there is a horse on the dining room table. However, the host does not wish to upset the guests by mentioning it and the guests do not wish to embarass the host so they all remain silent about the horse. Thus while trying to ignore it, the horse on the dining room table is uppermost in everyone's mind.

It's easy enough to carry the analogy a step further and realize that if the subject could be brought up, then questions, explanations, and feelings about the horse could be discussed. Dining and other conversation could take place without a preoccupation about the unspoken-of horse. It's also easy to imagine that hardly anyone would care to discuss the horse all evening, and certainly people would
tire of the subject if it were the only thing discussed evening after evening.

I have encountered problems associated with knowing when, how, and how often to discuss death and dying with my counselees. Before my first meeting with my first counselee, I did not know what to expect, although I imagined that some aspects of fears of dying or death would be part of the conversation. In any previous experience I had had as a counselor, the "presenting problem", whether it was marital difficulties, depression, or job dissatisfaction, was always discussed at the initial session. Being a Caritas volunteer "counselor" was different. I did not know how much or what part of my experience as a psychotherapist I should use with my counselee. I didn't have an exact role. So I decided just to fall back on being a person, and simply relate to the woman I was visiting. We had a nice get-acquainted visit, and she talked to me about her disease (cancer) in a tentative way. There was no mention of death and dying. What should I do? Should I try to get her "in touch with her feelings"? Should I challenge her "denial"?

My instincts said "No". Just let her be whoever she is. I was appalled that I needed to do something so badly, that I was having such a hard time just being with this person. But I realized how much I like "playing" therapist, helping people be more aware so they can make better life
choices. It was my need to confront any issues surrounding dying and death. It clearly wasn't on her agenda, for whatever reasons.

I was learning a lot on this first visit. I had no idea what she was getting out of it, but I was definitely having insights. I realized that, when I previously had been in a role as a psychotherapist, people had come to an office to see me, had felt called upon to say why they had come -- in other words, what their problem was -- and there had been an expectation that I would do something. In that situation, it was easy to confront an issue that seemed obvious, or just let go of the need to do something, and let them talk about themselves and their situation. Sometimes I had been uncomfortable in those first sessions as I got to know the person or persons, but I did have a role to play and that was comforting. During this first experience as a Caritas counselor, I was struggling to find a comfortable role.

Another insight was the realization that in one way this woman was no different than any other "client". She was checking me out, seeing if she could trust me. At least that was a possibility. Then I realized that I just could not let go of some theory to help me interpret what was happening, which was not much as far as I was concerned.
I finally relaxed. If we were going to ignore the horse on the dining room table, so what? It wasn't my place to bring it up. Not on the first visit. Not if I paid attention to the cues I was getting.

Finally all the busyness in my mind quieted down. For perhaps the last twenty minutes of a two hour visit, I felt comfortable. And she began to seem not like a cancer patient or a resistant client, or a woman in the stage of denial, or anything else except a person. And before I left she started to talk to me about being scared. She didn't say why she was afraid, she just said, "You know, I'm really scared."

That was a beginning, that first visit. For both of us. I'm continuing to learn about her and how I might help her. Once at a workshop taught by Charles Garfield (of Shanti) I asked for advice about this particular counselee because so often it just seemed that there was no movement, we weren't getting anywhere, she was saying the same things over and over week after week. He suggested I say to her that I want her to be the teacher -- ask her to help me to help her. So now when we are stuck, I say something like, "What would you like me to do for you?" "What do you need from me right now?" and her response takes us beyond the momentary impasse. I remind myself that I really can learn, and have learned, from her.
And I've learned that while I must remember to let the other person "be", I must also remember to let myself be. I bring as much of myself as possible into the relationship with counselees. And a lot of who I am is still that someone who likes to be a therapist, who likes to help people be more aware. So now I do that when it's appropriate. Or sometimes a person will be feeling really low physically or mentally, or in a lot of pain, or very sick, and she wants me just to sit with her. It's all part of the therapeutic process, whether I'm being confronter or comforter. "Healing occurs in relationship" (Koestenbaum, 1976, p. 155) and for me that expresses what being a Caritas counselor is all about -- a healing of spirit that is part of being in an authentic relationship.

It seems that most of the counselors in Caritas find their own way to be with their counselees and it's refreshing that we are not all following the same formula, except for listening to and learning from the counselee, and being ourselves. I probably use what could be labeled psychological techniques more than other counselors do. One reason for my use of these techniques is that my counselees are not in the terminal stage of disease, and often have difficulties of living rather than problems of dying, so I can use psychological techniques to help them. Another reason I use the techniques is simply that I have
training in psychology and so I bring that part of myself into the relationship with counselees. I'll give a few examples.

Once a woman kept talking about how she couldn't sit at her kitchen table any longer, a place she had always enjoyed. It was just too painful. She meant physical pain, and I knew perhaps that there was no more to it than that. But my intuition said there was something more, and I knew if I was wrong, I could only find out by saying something. So I asked her if she was willing to move into the kitchen and sit with me at the table. (I visit counselees in their homes. They have not been hospitalized except for brief periods.) She was surprised and a little resistant. I explained that I was only interested in whether she was willing to try something that I thought might help. She finally said she was. I felt that getting her to experience being in the kitchen would be more helpful than just talking about why she couldn't sit there any more.

We moved into the kitchen and when we sat down she became very anxious and began to shake. Sitting next to her and holding her slightly around her shoulder I encouraged her to shake, to just let it out and not try to stop it. Though she was obviously frightened and anxious, she continued to shake. The shaking was so powerful that she probably would have had to leave the room to stop it.
But she made no move to leave. In a few minutes the shaking stopped and she started to cry softly. Finally she became calm and relaxed. When she was ready, we talked about how she felt before, during and after the shaking. She became aware that her physical pain was not the main factor preventing her from sitting at the table. She realized that the beautiful view from her kitchen window as she sat at the table reminded her of all the life outside that she was missing, and by telling herself she "couldn't" sit at the table any longer, she was avoiding the pain of seeing life she felt cut off from. I could understand her reluctance to be faced with such unpleasant feelings. But she gained from her courage to try something that she thought would be painful and now has less trouble sitting in her kitchen. In that small, or not so small way, she can enjoy life more fully.

At other times I have used Gestalt dream work techniques, relaxation techniques, role playing, just about anything in my repertoire that fits. If the counselee resists, and my intuition tells me the resistance is sincere, I let go of the need to do a particular technique. With one counselee I am pushier, since she is forceful and capable of telling me when I'm out of line. With another I am more cautious since she will sometimes too easily conform to whatever someone else wants her to do.
Some principles of counseling or psychotherapy change when the counselee has cancer or some other life threatening disease. With any other type of client I would expect the relationship to end when our "business" together was finished. As long as my counselees have cancer (always allowing the possibility of a cure) I intend to be available to them. I will be with them until they die unless they no longer need me at some point. I doubt that I would have that attitude about a person not facing death. There would come a time that I would consider it "unhealthy" if she or he did not wish to end therapy. The "ending" of a relationship with a cancer patient is death or cure. Even in the event of a cure, I would keep in touch with these women (I have no male counselees at this time) with whom I have become so close, but only if the feeling were mutual, of course.

The relationship does not have to be equally intense through all phases of the disease, however. If I meet a counselee when she has first learned of her disease, this is likely to be an intense period. Just establishing the nature of the relationship also involves frequent visits. If a person lived for five years with cancer, for example, I doubt in that case that the same intensity would be maintained throughout the five years. I have a counselee right now who has a lessened need for my visits. She and
I have been through plenty of "heavy" sessions, she's now feeling pretty good mentally and physically, is getting involved in some new activities in her life and so we are beginning to meet much less frequently. If her situation changes we could go back to more frequent visits. It is also possible that her need for me is ending, regardless of her disease. The main point is that I agree with LeShan (1969) that it is detrimental to begin work with a "dying" person unless one is reasonably sure of being able to continue until the patient's need is exhausted, even though that may not be until death. It is a more total commitment than a psychotherapist would usually give to a client, but one that is necessary in thanatological counseling.

Another difference, at least theoretically, between a "dying" person seeking psychological help, and any other type of client, relates to motivation for change. It might seem that a person facing death is more highly motivated to change her or his behavior if the change promises the possibility of a sense of fulfillment at the end of life that was lacking during the rest of life. The change may even promise the possibility for a longer life, a second chance. What has the dying person to lose by making changes compared to the possible gain of an extended life or a better life in the time remaining?
In "non-dying" clients I have noticed a strong resistance when they are confronted with necessary changes they must make in order to achieve a "better" life. For instance, a father wants his daughter who is failing in school to do better. Through family psychotherapy, the father realizes his severe criticism of his daughter is contributing to her failure. However, he is unwilling (he would say unable) to be any different, and so continues to live with his frustration over his daughter's poor progress rather than change his behavior. A typical example more closely related to death and dying is that of the middle-aged, overweight smoker who wants to be healthier but will not change his long-standing habits in order to achieve health. I've noticed in these and similar cases that persons resistant to change feel somehow that they can change later, that faced with the difficulty of change, they would just as soon postpone it, or they rationalize that the change isn't necessary, that everything will work out without their having to change.

Is a dying person any different? Theoretically, yes, a person with a terminal illness is more motivated to make changes than another person who is not immediately facing death. A dying person realizes that time is running short, that s/he is not immortal after all and if life is to be any different, now is the time to make changes. However,
I am still observing this phenomenon and have realized that the issue is more complicated. Many people who do not have a life threatening illness often make profound life changes. And many people faced with death make no changes at all.

What then are the factors involved? At present I have no firm convictions and can only theorize. Perhaps anyone making a radical change designed to improve a life situation is in some form of crisis. A crisis can be internal, seen as arising from within the person, such as the realization of a less than meaningful life. Or a crisis can be external, seen as arising outside one's personal control, such as being fired from a job, or having a close relative die. But even if a person making radical changes is in some form of crisis, it doesn't necessarily follow that all persons in crisis will make changes. Perhaps they don't realize that change could help their situation. Perhaps change is more threatening than the crisis. Perhaps what others are viewing as a crisis is not perceived as a crisis by the person confronted with it.

Though I don't entirely understand the process, my conclusion at this point is that in those people I've seen make profound life changes some sort of an intense mind-body realization that change is needed has motivated them to change. This realization can occur to a person in any crisis and may never occur to some people, regardless of
the crisis. Finally, the diagnosis of a life threatening illness, more than any other life situation, may serve as a powerful catalyst to this realization of the need for change. The prospect of death may well be the most intensely motivating factor for change that there is. As I gain more experience with counseling, especially counseling the dying, I'll probably gain more insight into the issue of motivation for change.

Another issue that I have faced is whether to encourage a counselee to fight death or to accept death. I'll discuss this issue in the next section.

Fighting or Accepting Death

I call this my Simonton/Kubler-Ross dilemma--should a person work toward accepting death in the manner that Elisabeth Kubler-Ross so beautifully describes, or should a person try to fight cancer, or any other life threatening disease, with psychological means, as typified by the work of Carl and Stephanie Simonton?

Kubler-Ross (1969), in her chapter on acceptance, describes possible blocks to this final stage of peace. She talks of patients who fight to the end, struggling against the inevitable death, making it more difficult for them to reach peace and acceptance. She speaks of how family and staff may consider such fighting courageous and encourage
the dying person to struggle to the end. There are others who are ready to die only to have the family feel the person is rejecting them. One woman said "that the only reason that kept her still alive was her husband's inability to accept the fact that she had to die." (Kubler-Ross, 1969, p. 116). She was angry that he could not see her willingness to let go of life. After an operation was planned which the surgeons thought could prolong her life, and which her husband was desperate for her to have, she became much worse, weakening rapidly. In the operating room she had a psychotic episode, screaming, crying, expressing ideas of persecution until the planned surgery had to be canceled. Because of the psychotic episode her husband eventually came to realize he had to let go of her and was able to share this with her. She had less pain and was able to live her remaining time in dignity.

Kubler-Ross does speak of the other side of the dilemma--to know when a patient is perhaps "giving up too early", when "a little fight on his part combined with the help of the medical profession" could prolong his life. (Kubler-Ross, 1969, p. 114). She also speaks of the painful conflict when there is a "conveyance of hopelessness either on part of the staff or family when the patient still needed hope" (Kubler-Ross, 1969, p. 140), but these are isolated statements and generally she focuses on helping
patients and their families into the stage of acceptance of death.

The Simontons (1978), on the other hand, concentrate on showing cancer patients and others with serious diseases how they can participate in getting well again. They have observed four steps in the psychological process of recovery.

1. With the diagnosis of a life-threatening illness, the individual gains a new perspective on his or her problems.
2. The individual makes a decision to alter behavior, to be a different kind of person.
3. Physical processes in the body respond to the feelings of hope and the renewed desire to live, creating a reinforcing cycle with the new mental state.
4. The recovered patient is "weller than well."

...patients who have actively recovered from cancer...have a psychological strength, a positive self-concept, a sense of control over their lives that clearly represent an improved level of psychological development. (Simonton, 1978, pp. 71-73).

The program used by the Simontons to aid patients to recovery includes a realization by the patients of how they have participated in their disease, an identification of stresses prior to the disease, understanding the "benefits" of their illness, overcoming resentment, physical exercise, goal setting and relaxation along with mental imagery.

Visualization or mental imagery is a central element in the Simontons' approach. It is a simple and powerful technique. It consists of having the patients relax by the fairly standard method of becoming aware of their breathing,
then relaxing their bodies systematically from head to feet. In a relaxed state, the patients picture themselves in pleasant surroundings, then picture their cancer (or other disease) in whatever form fits for them, realistic or symbolic. Next they imagine the body's natural defenses and natural processes eliminating the cancer or disease. If they are receiving treatment, they also envision the way in which the treatment is helping them rid themselves of the disease. If they are experiencing pain, they picture the pain being soothed. They visualize themselves well, full of energy, proceeding toward their goals in life, and give themselves a "mental pat on the back" for participating in their recovery. They gradually come out of the deeply relaxed state, and when they are ready, continue with other activities.

This technique was first used in 1971 on a patient who was considered incurable. He practiced this method of visualization three times a day and finally overcame his disease, and is alive and healthy today.

I am very much drawn to this technique. I have successfully practiced relaxation and mental imagery for myself, with clients, friends and groups, usually to achieve heightened awareness, more energy, a greater ability to cope with life's stresses or simply a feeling of peacefulness. In my experience, imagery works. The desired
effect is often achieved, or at least some other unintended but also desirable outcome results.

I also have a strong bias against being a passive victim to anything, including disease. In addition I believe that within each individual are the truest solutions to her or his problems, mental, physical, emotional, social. Often an individual needs assistance and guidance, but reliance on the wisdom of the body-mind, with or without help from others, is a core philosophy of mine.

Because of a belief in what can work, and a bias toward what "should" be, I find myself at times wanting my counselees to adopt what would be my attitude (I imagine) if I were in their situation. I would fight the disease with whatever healing powers I could muster. I am torn because I know that as a Caritas counselor, my role is not to proselytize, whether it is religion or psychology. I could not support a counselor who insisted a person must accept Christ before death, for instance, so is there any difference in insisting that a person fight for health with psychological means? We are not a religious or a psychological group; we are a group formed to give support and caring to patients and their families.

I sometimes imagine that if my counselees were obviously in the terminal stage of disease that my attitude might be different. I might under those circumstances have
a need for them to quit fighting and seek the peace and acceptance that Kubler-Ross speaks of. Though I think I would fight and rebel against a disease such as cancer, I can also imagine that if it were apparent that death were imminent I would accept that and prepare for it.

The dilemma is: should I follow the ideas represented by the Simontons, or should I follow those of Kubler-Ross in counseling a person with a life threatening illness? The solution has presented itself over and over, but I am still learning it. First, I am not Carl or Stephanie Simonton nor Elisabeth Kubler-Ross. I must be myself. Second, acceptance of death and fighting for health are not in any real contradiction to each other. Resignation and fighting may be opposites, but acceptance and fighting are not. The real dilemma is knowing which attitude is appropriate in a given situation.

And third, I cannot be the judge of the appropriateness of acceptance or fighting, for another person. I can only listen to a person's needs and impart whatever information I have about possible approaches to a situation. The person will always know best for herself or himself. I must trust that. And I can offer myself as a guide or a support for the person, as I'm needed.
Quality of Life

There is one more aspect that I would like to explore in this section on counseling, the concern for the quality of each counselee's life. LeShan (1969) speaks of it as mobilizing the will to live in a patient. He believes that the psychotherapeutic approach of searching for the patient's strengths and what has blocked them--makes far more sense to these patients than does a therapy attitude that concentrates on the search for psychopathology and its causes. It gives the patients much more self-respect, strength, and hope; hope not so much for physical improvement, but rather for that spiritual improvement--in Maslow's term, "self-actualization"--that is the real core of our concern for ourselves. (LeShan, 1969, p. 849).

He believes that even though the patient is seriously ill, there are problems of life that have not been answered in a satisfactory way. He believes that the person has some unfinished business of life, psychologically, emotionally, or spiritually, so that help is really needed in terms of how to live, not how to die. He calls the fear of death the minor problem and the fear of life the major one, and that the therapist must be unafraid to confront both fears.

Clinical experience, according to LeShan, shows the wish to live a more powerful tool than being afraid to die in mobilizing the "life force". He suggests that the patient not be given false hopes in terms of physical recovery, but reassured that the therapeutic approach he
Advocates of expansion and freeing of the self can only have a beneficial effect. When patients grasp the goal of "the full rich self, the development of one's own being in one's own special way, the freedom to be oneself fully without fear" (LeShan, 1969, p. 849), they will find it a goal worth living for. The quality of their lives will be greatly enhanced, regardless of any change in their physical health, and they will be more able to fully experience the meaning of their lives as well as their deaths. Recovery and health are possibilities but the goal is a fuller and richer life, no matter how short, for the individual.

Most of what I have learned about helping a person with a life-threatening disease has come from the person herself, from the experience of other counselors, and from my own experience. It is not usual for me to gain a powerful insight just by reading. But LeShan had this effect on me. His idea of emphasizing the development of the full, rich self, and especially his notion of looking for strengths, not weaknesses in a patient as a means to helping them has become a guiding principle for me.

I had some experience with this notion previously. In other psychotherapy situations I had noticed how much more helpful, and often much more difficult, it was to have clients state, without qualifying the statements, three
positive things about themselves, rather than list all that was wrong with them. For me, LeShan's article crystallized the notion of stressing the positive.

One example of this occurred when I was helping a counselee overcome a block she had to practicing successful relaxation. Deep relaxation is beneficial for this counselee in increasing her feeling of well-being and as a step toward practicing imagery for control of pain and anxiety. Whenever she became relaxed, though, a rat would appear in her thoughts, distracting her and breaking her concentration on relaxation. In order to help her I had her practice her form of relaxation while I was present, to see if the rat would appear. After she began relaxing, her eyes suddenly opened. The rat had appeared in her images.

I decided to deal with the rat not by helping her expose whatever suffering, pain or ugliness it might represent but by putting it in its place, a place I considered secondary to the positive effort she was making toward relaxation. Thinking in terms of LeShan's ideas, her efforts toward relaxation and imagery represented the will to live, and the rat may have represented death or the fear of death. Thus to mobilize the "life force" that LeShan speaks of, it would be more appropriate to focus on continuing the relaxation, rather than focus on an exploration of the meaning of the rat.
I had her close her eyes and re-image the rat. I asked her simply to watch it for a while, not to fear it or regard it as having power to scare her and interrupt her relaxation. She watched it for a while and soon reported that it had disappeared. She went back to relaxation but the rat appeared again. We treated it once more in the same way, and it again disappeared. I helped her realize that her desire to relax, to grow in her ability to help herself through relaxation and imagery, was greater than the power of the rat to distract and block her positive efforts toward relaxation.

Perhaps the rat will become insistent enough that we will have to explore its meaning. But perhaps the stronger power of this woman doing something positive for herself will simply diminish the rat without having to attack it directly. I don't believe there is anything to be lost by first trying this positive approach. And what may be gained, as this woman discovers her strength to help herself, is a fuller, richer life for her, an improvement in the quality of her life.
INTEGRATING

Life as a puzzle to be solved has always been one of my favorite analogies. Recently I watched as my daughter began a new jigsaw puzzle. At first it was slow and difficult work, but as more and more pieces fit together, the puzzle became easier. Each piece began to fall into place sooner than the ones before, and the last few pieces fell readily into place.

Death and dying are parts of the puzzle of life that I'm working on at this time in my life. I'm trying to get to the place of understanding where the pieces will begin to fall easily into place. I feel that only to the extent that I have developed a philosophy of life and death that fits for me will I be able to help others find their way of facing death and dying as well as life and living.

Certain experiences -- my own, those of the women with cancer whom I counsel, and the experiences of other members of Caritas -- have been the most useful in helping me gain understanding about life and death. What I have read has been interesting and stimulating in most cases but rarely gave me any new insights. However, sometimes an author expressed essentially the same thoughts I have. For
instance, I'd like to quote from Kastenbaum and Aisenberg's preface to The Psychology of Death (1976).

The authors of this book became acutely aware of their own inadequate preparation as they entered into intimate contact with men and women who were living within the shadow of death. Very little in our educational background could be called upon for guidance. The fact that we were psychologists and therefore presumed to be expert in human thought, behavior, and interaction served only to emphasize our ignorance...

It was obvious that "book learning" would not have been sufficient...We had to increase our direct experience with people of all ages who were confronting a variety of death-related situations. We also had to reflect upon our own very personal relationships to life and death. (p. vii).

While I agree with Kastenbaum and Aisenberg's approach in general, occasionally they make statements with which I must take issue. For example, in their chapter on Facing the Thought of Death, they state,

There is just too much that we do not know, at least in that sense of the term "knowledge" that implies strong and clear research evidence. Some of us may "know" a good deal more than what can be demonstrated on the basis of "hard data." However, it remains for more systematic and sophisticated research to help us distinguish between the real and the wax fruits of clinical intuition. (Kastenbaum and Aisenberg, 1976, p. 105).

I agree that some of us know more than hard data can show, but I believe there is a real bias in our culture toward "strong and clear research evidence" being the ultimate authority. I believe this reliance on that which can be "scientifically" proven can detract from our ability to relate on a meaningful, humanistic level, to others and
to life. In my opinion a better authority to rely on is one's own perceptions, one's innate ability to correctly interpret the significance of any events, teachings, and experiences to which one is exposed. As Lowen (1972) says,

I feel that the balance has shifted strongly against the natural life forces: understanding, pleasure, body, nature, and the unconscious. We are committed to more information without any safeguards that would protect our understanding. Doing research that is merely a gathering of information together with its statistical juggling has become the supreme goal of our higher educational programs. Fortunately most of the Ph.D. theses that are written are never looked at. Yet the insidious effect of this focus on data is a progressive loss of faith in the natural capacity of the human being to understand himself, his fellow man, and his world...We can and we must rely on our senses if we are to make sense out of the confusion of our existence. (pp. 233-234).

Elliot (1972) expresses a similar idea.

Of the ways in which we can think of knowing or understanding...one is to "know all the facts", another is to ask the question, "how does it relate to me?" (p. 117).

A question I often ask is How does this feel to me? Does this (whether "this" is counseling, reading, thinking, or listening to someone else's ideas or experience) seem right, does this fit for me, does it make sense? This approach keeps me in touch with how valid the experience or idea or event is to me personally. Through this method of seeking to understand by trusting my own wisdom I continually grow in confidence that I'm building a meaningful and worthwhile philosophy. The shape and form
of the puzzle pieces become clearer and the pieces become easier to place together.

I'd like to share some of the philosophy I've put together for myself concerning death and dying. The basic question of why do we die, seems to me at this time to be answerable by observing that becoming, being, changing and dying are simply part of nature. Trees, insects, flowers, clouds, animals, and people all seem to go through the cycles, each according to its particular nature. I am becoming content with the realization that these natural cycles are exactly as things should be.

And what of after death? Does the soul or spirit of a human survive? I am uncertain on this point. I observe that others believe this, and I often talk as if I do also, but I am not certain. I believe in out-of-body experiences, so if the soul or essence or whatever name one uses for spirit, can survive as separate from the body for some length of time, then perhaps it is possible for this essence to survive after death. If so, is the person consciously aware of the change and aware of the previous existence? I am still exploring all the aspects of this part of the puzzle.

However, all of what I believe or know or cannot yet discern influences my present life. Since I am not sure about an afterlife I do not expect to necessarily have any existence other than the one I now am aware of. So I feel
I must fulfill my nature, the general nature of humanness and my particular nature as an individual human being, as best I can here in this life. Certain elements of loving, sharing, striving, understanding and knowing seem intrinsic to my nature so I try to be true to what seems right for me.

I am also curious about what death will be like for me. From observing others' deaths and paying close attention to what those who are dying have to say, I have noticed that there is a pattern to one's death that follows the pattern of one's life. Some people seek to change the pattern when confronted with death and succeed in doing so, thereby temporarily avoiding death, or changing the quality of the life that remains. I have decided for myself that I wish to live in such a way that I do not have to make radical changes in my lifestyle at some future time of crisis. I prefer to continually refine my lifestyle now so that is is satisfactory to me, and trust that when death comes it will be appropriate to how I have lived and will be acceptable to me. I sometimes fear I am not living in accordance with this philosophy, but I still believe that for me this is the best way to live and so I seek to follow what seems to be my path.

Finally, and in some ways most importantly, I am trying to integrate into my life the way in which I can best help others with their living and dying. For now, taking into
consideration my unique abilities and limitations, I feel that I can help others know that they too have the power to discover what is right and fitting for them, and I can support them in their endeavors to follow their own best instincts for how to live and how to die.

Basically, I feel more whole and integrated within myself the more I work on this puzzle and try to integrate aspects of life and death. I feel that the pieces will, and sometimes already do, fall nicely into place. The pattern of living and dying continues to be revealed and I feel happy to be part of the pattern.
"Life is process, not goal" is one of my guiding principles, and so the process goes on -- of learning about death and learning how to share what I know. I feel as though in this paper I've taken some time out to try to convey a sense of what's involved in my work with a group organized to provide counseling services for those facing death. I have left out many aspects of the work Caritas does, but I've stayed with what was personally relevant.

I have tried to relate the importance my psychological background has in my work with Caritas, even though psychological help is not the group's main concern. And I've shown some of my struggles with keeping psychological issues in perspective.

Also, I wanted to share with the reader the process I use for integrating aspects of my life and work into a wholeness. I wanted to share a sense of the philosophy I'm developing by facing and not ignoring the realities of living, dying, and death.

I have no real conclusions to make. This project is on-going. I am still a member of Caritas and will be for some time. I am still learning about life and death, and
though the focus may change from time to time, I hope to be open to learning throughout my life. For the present, a certain thought seems to stand out as significant -- the awareness of my own mortality. This awareness that my present life is limited, that death will surely occur, increases for me the importance of trying to make every day, every experience worthwhile. The people I've been privileged to know, who because of a life threatening illness have had to face their own mortality, have taught me that ultimately it is the quality and not just the quantity of life that matters. Each of us must decide personally the definition of quality.

The experience of exploring issues of death and dying has increased the quality of my life. This project has thus been very valuable to me and I hope my work has also helped others.
REFERENCES

Articles of Incorporation of Riverside Community Caritas, Inc. 1979.


