

# **Psychotherapy with the Dying Patient**

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"There are no inflexible rules that do not contradict the principle that dying is an individual matter, and therefore should be individualized. Management is most appropriate when the therapist at the outset projects his imagination into the future toward the "Omega Point" and considers when, where, how, and with whom this inexorable death ought to occur."

A.D. Weisman (1)

### **INTRODUCTION**

Psychotherapy with dying patients shares many features with all other psychotherapy. However, the unique status of the dying person presents special problems for the mental health professional. Clearly, everyone will die, and in this sense all therapy is done with patients of a limited life span. The labeling of a person as a "dying patient", identifies that person as belonging to a special category of humanity, and creates profound changes in the emotional, social, and spiritual climate of therapy. The dying person is one who is seen to be in a life-threatening condition with relatively little remaining time and little or no hope of recovery. This unique existential position of the dying person necessitates some adaptations of the typical psychotherapeutic attitudes and strategies. The goals, structure, and process of therapy must change to meet the special needs and circumstances of the dying patient.

How does therapy with a dying person differ from "typical" therapy? There are several features which distinguish it.

- \* First, therapy is more time-limited and time-focused. The dimension of time takes on special urgency with the dying patient. While many therapies are time-limited, often they proceed as if time were an inexhaustible resource. The brief remaining time for the dying patient intensifies the therapy process, and accelerates it.
- \* Second, the goals of therapy with dying patients are often more modest. Recognizing the limits of possible change is an essential feature of therapy with the dying. What can be accomplished is quite restricted by time, disability, and other aspects of the patient's condition.
- \* Third, the treatment of the dying patient often requires careful coordination with a variety of medical, nursing, and pastoral professionals. The physical condition, medical treatments, and institutional settings of the patient complicate the practical and psychological context of therapy.

### **THERAPEUTIC APPROACHES**

Prior to Elisabeth Kubler-Ross' seminal work, "On Death and Dying" (2), very little systematic attention had been given to psychotherapy with dying patients. One important exception to this neglect was the humanistic approach described by Bowers, Jackson, Knight, and LeShan in their book, "Counseling the Dying" (3). The prime impetus, though,

was certainly Kubler-Ross, who provided an integrated theoretical and therapeutic perspective for use with the dying patient. Following her lead, hundreds of books and articles have appeared in the last decade. Reflecting the increased maturity of the field, there are presently many therapists and researchers focusing on this population, and in addition several scholarly journals which devote some attention to the care of the dying person. Psychotherapy is beginning to be incorporated into the more general and growing field of clinical thanatology, which is concerned with the overall care and treatment of the dying person - mind, body, and spirit. (4, 5)

Modern psychotherapies are divided into four main groups - psychodynamic, humanistic, behavioral, and family therapy. The main features of these therapies as used with all patients are preserved in the treatment of the dying, but each has been modified somewhat to fit the unique needs of dying persons.

### **The Psychodynamic Approach**

The psychodynamic approaches are primarily concerned with the emotional conflicts and defense mechanisms of the individual. Special issues of conflict and defense arise in the dying person, and this approach addresses them in the hope of resolving the psychic crisis to the fullest extent possible. Dying is the ultimate crisis of ego development, and as such is associated with intense infra-psychic turmoil. Psychoanalyst Erik Erickson labels the last stage of ego development, "ego integrity versus despair", and identifies it with the crisis provoked by the confrontation with one's mortality. The fear of death may precipitate a breakdown of previously integrated ego functioning, and result in an attitude of despair and disgust. (6)

In most people the threat of death generates powerful defensive reactions, and although these defenses provide some limited relief of emotional distress, in the end they prohibit the person from effectively coping with the death crisis. Common defenses which are found in the dying person include denial, displacement, projection, and regression. As Kubler-Ross pointed out, denial is a very typical reaction of the dying person. The refusal to accept the reality of death makes it impossible for people to prepare themselves and their families adequately for it.

Through the displacement defense the fear of dying is channeled into other, "substitute" fears. For example, one may become preoccupied with anxiety about family members, personal business, household jobs, or other matters, and, thus, obtain partial release of one's death anxiety. The dying person's projection defense typically expresses itself in hostility and resentment toward others, e.g., doctors, nurses, and family. The person may irrationally blame others for the illness, or accuse them of not doing enough to cure or help. Regression in the dying person is often manifested in increasingly immature, dependent, and occasionally self-threatening behaviors and attitudes. An example is the extremely helpless, "infantilized" position of the person who has completely given up and merely waits for death.

A major goal of dynamic therapy with the dying is to help the person recognize, confront, and replace the defenses *which* run counter to an emotionally healthy attitude toward death. In the process it may be necessary to try to work through some long-standing problems and fixations which are intensified by the death crisis. For instance, a patient with a history of anxiety over separation from family members may be more distressed over the issue of loss/separation than by other death-related concerns. Dynamic

therapy with dying patients is not directed as much toward the goal of insight, as it is with others. Time limits the course of therapy with the dying, and the goals are therefore more short term changes; rather than long-term personality change. The strategy of Kubler-Ross is a good model of a dynamic approach to defenses and emotional conflicts in therapy with the dying. (2, 7)

"On Death and Dying" provides many wonderful examples of a therapeutic approach that begins by accepting the defensive position of the patient, and then proceeds to work with the patient to overcome the self-defeating results of those defenses. Below is an example of one of Kubler-Ross' cases:

Mr. O. was a successful businessman dying of Hodgkin's disease. During his stay in the hospital he behaved like a tyrant with his family and the staff. He blamed his cancer on his own "weakness" and claimed that "it was in his own hands to get up and walk out of the hospital the moment he made up his mind to eat more." His wife consulted with Dr. Ross for help in dealing with his domineering behavior.

"We showed her - in the example of his need to blame himself for 'his weakness' - that he had to be in control of all situations and wondered if she could give him more of a feeling of being in control, at a time when he had lost control of so much of his environment. She did that by continuing her daily visits but she telephoned him first, asking him each time for the most convenient time and duration of the visit. As soon as it was up to him to set the time and length of the visits, they became brief but pleasant encounters. Also, she stopped giving him advice as to what to eat and how often to get up, but rather rephrased it into statements like, "I bet only you can decide when to start eating this and that". He was able to eat again, but only after all staff and relatives stopped telling him what to do".

As Mr. O. began to regain a sense of control over his environment and his activities, his anger, guilt, and tyrannical behavior decreased, and his relationship with his family improved.

Another significant concern which has been addressed by the psychodynamic approach is countertransference, the emotional reactions of the therapist. The therapist must be particularly careful to avoid letting personal fears and conflicts over death interfere with helping the patient. The three potential negative results of countertransference are:

- 1) The therapist unwittingly supports the patient's denial of death by avoiding the issue.
- 2) The therapist regresses to a helpless position in doing therapy with the patient.
- 3) The therapist engages in an anxious avoidance of the patient and his concerns.

In order to minimize the effects of the therapist's own attitudes toward death on the therapy, the therapist should explore and confront personal death attitudes before initiating treatment. (8)

## **The Humanistic Approach**

More than other approaches the humanistic view of therapy clearly integrates a philosophy of human nature in which death plays an essential role. Existentialism is a philosophy which has had a significant effect on the humanistic approach, and in this philosophy living the "good life" demand a confrontation with the reality of death. Death awareness helps us to clarify our values and purpose in life, and motivates us to live our lives with fullness and meaning. Death is the absolute existential threat, and it forces us to acknowledge the limit of our life plans and face "nothingness". (9)

Humanistic therapy aims to help the dying patient live as full a life as possible in the face of death. Without giving false hope or optimism, the therapist attempts to mobilize the patient's will to live, to encourage the expression and growth of the self, and to facilitate the patient's self-actualization (10, 11, 12). LeShan, an advocate of this approach, expresses his view of humanistic therapy with the dying in the following remark:

"Help is really needed in terms of how to live, not how to die." (10)

With the dying patient humanistic therapy is more intensely focused than with others. According to LeShan psychotherapy should "move strongly" with the dying patient. An example of his approach is given in this dialogue.

Patient (P): "I'm afraid of my cancer. I want to live

Therapist (T): "Why? Whose life do you want to live?"

P: "I detest it! I've never lived my own life. There was always so much to do at the moment. So much to ...I never got around to living my life."

T: "You never even were able to find out what it was."

P: "That's why I drink. It makes things look better. Not so dark."

T: "Maybe the better way would be to find out what is your way of life and start living."

P: "How could I do that?"

T: "That's what we are trying to do here." (10)

Feigenberg describes the main features of his humanistic, "patient-centered" approach in the following way:

- 1) It emphasizes building a strong, supportive, and empathic relationship with the client.
- 2) It allows the client to set the pace of the treatment.
- 3) It enables the client to actively and positively participate in the process of dying. (13)

## **The Behavioral Approach**

The behavioral approach to therapy relies on educating patients about more adequate coping skills to help deal better with the death crisis. Impending death is a

terribly stressful situation, and it produces extreme emotional reactions like anxiety and depression, which inhibit patients from living out the remainder of their lives in a satisfactory way. The symptoms of the dying patient are partially manageable through some standard behavioral techniques. For example, relaxation training and desensitization can help to alleviate excessive fear and tension. Other self-management skills, like biofeedback and self-hypnosis, are also useful in controlling the distressing emotions of the patient.

One example of a valuable behavior therapy technique is "stress inoculation training". With the dying patient this strategy may be used to help cope with the physical and emotional aspects of pain. In this approach the patient is taught how to employ cognitive and behavioral skills in preparing for pain and managing pain. Some of the "self-statements" learned in this technique for pain control are shown below.

#### Preparing for Pain:

"What is it I have to do?"  
"I can develop a plan to handle it."  
"Just think about what I have to do."

#### Confronting and Managing Pain:

"I can meet the challenge."  
"Just handle it one step at a time."  
"Just relax, breathe deeply."

#### Self-Reinforcing Statements:

"Good, I did it."  
"I handled that pretty well."  
"I knew I could get through it."

A basic goal of behavior therapy is to provide some Coping skills so that the patient can reduce discomfort and gain a measure of control over life. The loss of control over one's body, one's actions, and one's future which is experienced by the dying patient can lead to emotional distress and to feelings of helplessness and passivity. The acquisition of productive coping skills will not only enable the patient to manage negative feelings better, but can also improve self-esteem by providing a sense of competence and self-efficacy.

The behavioral approach to therapy tends to focus on specific and concrete symptoms. It does not directly attend to the developmental and personality issues which are so important in dynamic or humanistic approaches. The goal of the therapy is primarily to relieve negative emotions and to enable the patient to cope more effectively in the remaining time. (14, 15)

## Family Approach

The impending death of a family member places the entire family in a state of crisis. Death presents a threatening situation for each member of the dying person's family. The degree of disturbance in the family depends on many factors such as the role of the dying member, the stage of development of the family, and the quality of relationships among family members. A family systems approach conceives of the entire family, not just the dying person, as the recipient of therapy. This approach seeks to provide the family unit the opportunity to learn to deal with the tragedy. Some therapists will continue treatment beyond the death, offering grief counseling for the survivors.

Though family therapy may be integrated into therapies of various types, there are several issues on which family therapists are more likely to focus. Dying patients often experience a need to feel the closeness and support of their families in facing the death crisis. In families where past conflicts have interfered with relationships between the patient and others, family therapy can facilitate more open and productive communication. This can benefit all members concerned in terms of finding closure for "unfinished business". The defenses of family members can make it very difficult for the dying patient to confront death. It often happens that family members share the defensive reactions of the dying person, such as denial of the facts and displaced anger.

An advantage of the family approach to therapy is that it offers an experience that may enable everyone to accept the facts and to work together to enhance the quality of life for the dying person. Families generally experience a range of intense emotions regarding the dying patient, including anger, guilt, fear, and depression. In family therapy members are encouraged to understand and express these feelings in anticipation of the death of their loved one. (16)

As she was in many other areas, Kubler-Ross was a pioneer in involving families in the therapeutic process with the dying. The case below, from Kubler-Ross (2), illustrates some common emotional dynamics in families with a terminally ill member.

"I am reminded of an old woman who had been hospitalized for several weeks and required extensive and expensive nursing care in a private hospital... Her daughter was torn between sending her to a nursing home or keeping her in the hospital, where she apparently wanted to stay. Her *son-in-law* was angry at her for having used up their life savings... When I visited the old woman she looked frightened and weary. I asked her simply what she was so afraid of ... She was afraid of 'being eaten up alive by the worms'. While I was catching my breath and tried to understand the real meaning of this statement, her daughter blurted out, 'If that's what's keeping you from dying, we can burn you' by which she naturally meant that a cremation would prevent her from having any contact with earthworms. All her suppressed anger was in this statement."

Kubler-Ross encouraged the mother and daughter to communicate honestly for the first time about their individual concerns, and they were able to console each other and make arrangements for the mother's cremation. The mother died the next day.

## MAJOR THERAPY ISSUES

### The Psychology of the Dying Person

The best known theory of the dying process is that of Kubler-Ross, who proposes that many dying people progress through five stages of dying, described below:

1. Denial. Initially the reaction is "No! Not me!" Though the denial is rarely complete, most people respond with disbelief in the seriousness of their illness.
2. Anger. In this stage the dying person expresses anger, resentment, and hostility at the "injustice" of dying, and often projects these attitudes onto others.
3. Bargaining. The dying person tries to "make deals" to prolong life, e.g., making promises to God.
4. Depression. Here the individual may become overwhelmed with feelings of loss, hopelessness, shame and guilt, and may experience "preparatory grief".
5. Acceptance. In the final stage one comes to terms with death, not necessarily happily, but with a feeling of readiness to meet it.

Some researchers have questioned the generality of Kubler-Ross' five stages, pointing out that they do not necessarily apply to all dying people and that the therapeutic implications of the theory are not necessarily appropriate for everyone.

An alternate view of the "trajectory" of the dying person is offered by the psychiatrist, Avery Weisman (5). He believes that Kubler-Ross' theory describes some common reactions to loss, rather than general stages of dying. Weisman proposes four very flexible stages:

1. Existential Plight. The dying person experiences an extreme emotional shock at the awareness of his/her own mortality.
2. Mitigation & Accommodation. The individual attempts to resume a "normal" life after first learning of the terminal nature of the illness.
3. Decline & Deterioration. When illness and its treatment begin to take full control over one's life and normal living is no longer possible, this stage begins.
4. Pre-Terminality & Terminality. This final stage refers to the very end of life, when treatment is no longer helpful and the "death watch" begins.

Whether they accept stage theories or not, most researchers and practitioners recognize that there are many common features in the emotional reactions of dying people. The core emotions on which therapies focus include depression, anxiety, and anger (17, 18, 19, 20).

**Depression.** Depression is perhaps the most typical response of the dying person. Although they are not inevitable, feelings of hopelessness and powerlessness pervade the experience of most dying people. The physical impairments that result from terminal illnesses and the restrictions on hospitalized patients only add to these feelings. The mental and physical condition of the dying person fosters a sense of alienation and withdrawal.

Patients may slowly become estranged from family and friends, and they begin to disengage from "normal" living at the point where death is the prognosis. Depression

is also associated with the loss of control over life events experienced by the patient. As death nears it is easier to slip into a state of passive resignation and despair. The potential of suicide is also a matter of great concern. The demoralization, hopelessness, and physical pain of the dying patient contribute to a greater risk for suicidal action. The relatively high rates of suicide among the elderly may reflect depression in this group because of the infirmities of old age.

**Anxiety.** For most people the thought of death provokes anxiety. In facing death people typically experience a wide range of anxieties and related emotions like fear, dread, and panic. An analysis of the anxiety of the dying person identifies several central concerns. Surely, everyone confronts death in a unique way dependent on one's individual needs, personality, culture, and social situation, but the majority of dying persons experience intense feelings of anxiety and associated emotional stress. Some of the common elements of this anxiety are described below:

\* The physical condition of the patient is certainly an obvious and significant source of anxiety. Pain, suffering, and the physical debilitation of the terminally ill person contribute significantly to insecurity, stress and anxiety. In addition terminally ill patients whose medical treatments are painful or aversive, e.g., chemotherapy for cancer victims, may develop conditioned anxiety reactions to the treatment setting and anticipatory anxiety regarding further treatments. Anxiety and shame can also result from the physical changes which occur in the dying person. The patient who insists "I don't want anyone to see me like this!" may be expressing a fear of rejection by others because of unacceptable bodily alterations from the illness.

\* The social dimension of anxiety is also an important issue with the dying. Many worry about the effects of their illnesses on family members and friends. For people whose social roles are critical to the well-being of others anxiety over others may be as pronounced as self-concern. For instance, a single mother with two young children is quite likely to experience great fear for the future and safety of her children. Another aspect of social anxiety in the dying -involves the fear of loss and disruption of relationships. As suggested above social anxieties may be due to anticipated rejection because of physical revulsion, or to other factors, e.g., the fear of not being needed or wanted by others.

\* The spiritual and existential aspects of death anxiety are also part of the psychology of dying. Questions about the meaning of one's life and the possibilities of life after death are common concerns of the dying person. It is not unusual for people to show sudden increases in religious feelings when facing the prospect of personal annihilation. In dealing effectively with these concerns psychotherapists do well to cooperate with the clergy and pastoral counselors, who are proficient in helping people through religious crises.

**Anger.** In Kubler-Ross' model anger is an essential stage of dying. The disorganization of and threat to life felt by the dying person generates frustration, resentment, and hostility. These emotions can easily be turned against others or turned in on the self. Family members, friends, hospital staff, and therapists are likely to bear the brunt of this anger. The reactions of the recipients of anger may include withdrawal, anxiety, defensiveness, and anger in return. This will only complicate an already tension-filled situation. When the patient's anger is internalized, it leads to self-recrimination, self-blame, guilt, and lower self-esteem. As many psychologists have pointed out, anger

turned on the self often fuels depression. The anger of the dying person is not always focused on others or the self, but is for many a diffuse, untargeted feeling. The pain, injustice and absurdity of dying cannot always be blamed on anyone or anything but the human condition, and that cannot be changed.

A case reported by Kubler-Ross (2) illustrates some of the common features of a patient's anger.

Bob, a 21 year old cancer victim, was troublesome with the staff and other patients. His intense hostility prompted Kubler-Ross' consultation with him. On seeing his collection of "Get Well" cards she asked him, "Bob, doesn't that make you mad? You lie on your back in this room for six weeks staring at this wall with these pink, green, and blue get well cards?" "He turned around abruptly, pouring out his rage, anger, envy, directly at all the people who could be outside enjoying the sunshine, going shopping, picking a fancy get-well-soon card. And then he continued to talk about his mother who 'spends the night here on the couch. Big deal! Big sacrifice! Every morning when she leaves, she makes the same statements - "I better get home now, I have to take a shower!" 'And he went on, looking at me, most full of hate, saying, 'And you too, Dr. Ross, you are no good! You, too, are going to walk out of here again.'

What counsel and advice can be offered to the dying person who experiences these intense emotions, and the many associated problems accompanying them? Often, the answer depends on the theoretical orientation of the therapist. As discussed earlier, different theories recommend different strategies for treating emotional distress. Behavioral therapies can assist the patient to take some control over these feelings through techniques like desensitization, stress management, and relaxation training. Even a small measure of control can improve the condition of the patient. Humanistic therapists seek to help the patient confront death in as active and positive a way as possible, relying on an exploration of the individual's values, goals and self-understanding. Dynamic therapy attends to the defensive reactions of the patient, and attempts to overcome self-defeating defenses in order to help the patient through the dying process.

Despite considerable diversity in theory, the practical demands on counselors of the dying have led to some common concerns. As a rule therapists working with dying people take an "eclectic" approach - they choose from various theories those ideas which are most applicable to the individual needs of their patients.

If there is one fundamental principle of therapy with the dying person, it is to facilitate communication about the person's needs. A primary task of therapists is to assist patients in meeting their individual needs in their remaining time. Of course, each one has different needs, depending on life history, personality, and many other factors, but there are some common needs shared by most dying people. These needs include, but are not necessarily limited to, security, affection, support, dignity, and self-expression.

## **Psychosocial Context of Dying**

Dying, like other aspects of life, is uniquely conditioned by numerous individual differences. In discussing this uniqueness the term "life context" may be used to capture the complex aspects of the patient's life which influence the process of dying (16). Two psychosocial dimensions of the life context will be explored here - the developmental and the treatment contexts.

### **The Developmental Context**

Dying is often assumed to be a problem of the elderly. Although this is generally an accurate assumption, much of the attention of psychotherapists working with the dying has been directed at groups other than the elderly. The age of the person is an important therapeutic factor insofar as it determines the needs of the patient, the reactions of the family, and attitudes of treatment staff. Specific therapeutic issues will be considered for three age groups - the elderly, adults, and children.

**The Elderly.** The elderly person, having reached what is usually thought to be the "normal end" of life, is more likely to see death as a timely, though not necessarily welcome, event. The perceived timeliness of death is an important variable in the patient's and others' reactions to the process of dying (5). Death is not typically desired by the elderly person, but it is more likely to be accepted. The families and friends of the elderly dying person tend to view death as less tragic and threatening than in the case of a child or young adult. Unfortunately, in our society the elderly are an undervalued group, and this is reflected in the attitudes toward death in this part of the life span. The death of an old person is usually less disruptive of normal family processes, because of the marginal economic and social roles of the elderly.

In therapeutic work with this group several important age-specific problems arise. The combined effects of old age and terminal illness can produce extreme physical handicaps which are both painful and emotionally distressing. The loss of physical control over one's body is a frustrating, embarrassing, and depressing experience. Given a marginal social role and terminal illness the elderly person can easily experience a sense of uselessness and unimportance in the final months of life. One way to alleviate these concerns is to enable elderly patients to become actively involved in the decisions which affect their lives, and to encourage them to participate as much as possible in their treatment programs. (21, 22, 23, 24)

For this group a common therapy concern is "unfinished business" with family and friends. Unresolved problems, unhealed hurts, and incomplete plans can haunt the person near death, and can lead to profound emotional distress. Therapy can offer opportunities to examine their unfinished business, to work toward resolutions where possible, and to accept failures where necessary. The "life review" is one therapeutic strategy to help accomplish these goals. Looking back over one's life, reflecting on it in a positive way, and integrating one's understanding of life can help the person through the death crisis in a self-enhancing way.

"Use of the life review in therapy has produced impressive changes: A 78-year-old man, optimistic, reflective, and resourceful, who had significantly impairing egocentric tendencies, became increasingly responsive in his relationships to his wife, children, and grandchildren.

These changes corresponded with his purchase of a tape recorder. Upon my request he sent me the tapes he had made, and wrote: 'There is the first reel of tape on which I recorded my memory of my life story. To give this some additional interest I am expecting that my children and grandchildren and great-grandchildren will listen to it after I am gone. I pretended that I was telling the story directly to them' ". (25)

A common therapeutic concern with the elderly patient is depression. Some have attributed depression among the elderly to a developmental process of the last stage of life. "Terminal drop" (26) and "psychogenic mortality syndrome" (27) are two labels for this process in which the person begins to show psychological deterioration, withdrawal from family and friends, and general disengagement from living.

Whether or not depression is a "natural" part of these more general reactions, it is nevertheless a major mental health problem for the elderly in our society. As suggested earlier, the sudden increase in suicide prevalence among the elderly may be a reflection of the high rate of depression. In addition to the numerous reported cases of suicide, it is likely that there are many uncounted "silent suicides" among this group - deaths due to self-destructive or neglectful behavior which do not appear to be intentional suicide.

**Adults.** Adults who are dying in the "prime of life", rather in advanced age, present quite different needs and problems to the therapist. The adult with family responsibilities who is stricken with terminal illness and the octagenarian in a nursing home face their deaths with distinctive concerns because of their ages. The sense of loss, injustice, and anger is apt to be more intense in the person at this "middle" stage of life. The loss of family, career, identity, and the expected future are typical concerns of the dying adult. It is more common for the middle-aged adult to be role-identified than for people at other ages. The structure and meaning of adult life is often grounded in job and family roles. The dying adult is removed from those activities which provide security, identity, and purpose in life.

The effects of dying on family members are also different in this age group. When the person is actively engaged in the responsibilities and relationships of family life, the threat of death creates extreme stress on the entire family system. Kubler-Ross reports a case in which this is evident:

"The first example is Mrs. W., a twenty-eight-year-old mother of three small preschool children. She had liver disease and because of her liver disease, she slipped in and out of hepatic coma, confusional states, and psychotic episodes. She was a young woman who felt that she was too young to die. She never really had the time to be with her children. During these times of confusion she was totally disoriented. She went in and out of the hospital; her husband took out of the hospital; her husband took out a loan to pay for the hospital and doctor bills. He had babysitting problems, and he finally asked his mother to come into the household and take care of children. The mother-in-law did not tolerate the daughter-in-law well. She would have liked to get it over with as soon as possible.

The young father was in great distress because of his financial problems and the whole mixed-up state of the household. One day he came home from work tired

and desperate, and he blurted out to his dying wife, 'It would be better if you would live and function as housewife and mother for one single day than drag out this misery any longer!' This young mother sensed that her husband counted the days; the mother-in-law wanted to get it over with as soon as possible; the three children did not make it any easier, but they made her feel even more guilty for dying on them." (7)

Therapy with dying adults generally aims to "normalize" the patient's life as much as possible. Patients need to remain as fully engaged in the routines of living as they can. It is important to help them preserve as much involvement in the roles, habits, and responsibilities of daily life as they can manage. Of course complete normalization is impossible, but depending on the individual's situation, it is important to help mobilize the patient for living fully in the remaining time. Family involvement is especially important. Dying adults are understandably worried about spouses and children, and the effects of death on them. Concerns about financial matters, funeral arrangements, and household responsibilities are commonplace. Dying adults need assurance that their families will be secure after they are gone.

**Children.** There are few events like the death of a child which provoke such intense emotions and exert such powerful effects on family, friends, hospital staff, and therapists. The therapy needs of dying children vary greatly with age, illness, personality, and family factors. Toddlers and infants respond to their dying mostly in terms of the reactions of family members. The lack of understanding of death in the very young child limits the range of emotional reactions to dying. The young child's conception of death is quite vague and magical, and the feelings about dying are more often fears of separation from parents. In addition the fear of physical pain and suffering needs to be managed in therapy, as well as the behavior of the dying child, e.g., compliance to hospital rules and medical advice.

With increased maturity and self-awareness the school age child begins to perceive death as a more permanent and concrete event. At this age the child may view dying as a punishment for wrongdoing, and experience remorse, guilt, and shame. Through middle childhood the concept of death becomes more defined as a final and irreversible event. By age 10 children generally will conceive of death as permanent, and with this awareness comes a more intense and personal emotional response to dying.

Dr. Bluebond-Langner, an important researcher in this area, describes five stages of understanding that children undergo in their awareness of the meaning of death:

1. An understanding that the illness is serious.
2. An understanding of the drugs and their side-effects.
3. An understanding of the purpose of treatment procedures.
4. An awareness of phases of relapse and remission.
5. An awareness of their own eventual death. (28)

From late childhood through adolescence there is a greater concern of the dying child with the physical aspects of the process. The fear of pain and physical disability emerge as central concerns. A related problem that is most apparent in teenaged patients involves the association between body-image and identity, and the feelings of shame and disgrace over their physical conditions. For the terminally ill adolescent there is an acute sense of the injustice of death. Dying teens rightly see themselves as being cheated out of a future, and this hard to accept. Hostility and aggressive behavior is not unusual for this group, and these feelings certainly need to be addressed. (29, 30)

Therapy for the dying child must be adjusted to the developmental level of each patient. In general therapists seek to provide information, support, and solace for the dying child. The child needs accurate facts about the illness and treatments, but obviously communications of this sort must be appropriate to the child's capacity for understanding. The discussion of death and dying with the young child is best approached by letting the child lead with questions, and giving direct answers to them without overloading the child with information too advanced for comprehension. The role of parents in these discussions is extremely important, especially for the very young child.

Emotional support is also a goal of therapy with dying children. The emotions of the child may be overwhelming and confusing. Children need to feel security and support in the therapy so that they may openly express their concerns and fears. For younger children play therapy is a good strategy to enable them to work on their emotions. Therapists should provide the child with opportunities to experience positive feelings of success and control to enhance the child's self-esteem and confidence.

Attempts to normalize the child's life may also help. For example, it is beneficial where possible to maintain the family and educational activities in which the child is involved. For older children and teens help can be gained through the use of peer group meetings.

For dying children therapy needs to address the concerns of the family. Family members are essential for effective therapy with children. However, family members must be helped to deal with their own problems regarding the child's dying. In a family therapy approach both the dying child and others in the family learn to communicate openly with one another. Parents often must be helped to manage their feelings of anger, guilt, and helplessness, as they learn to help their child. (31, 32, 33)

### **The Treatment Context**

Everyday reality is obviously quite different for the dying person, and a central fact in the difference is that of "treatment". The primary social role of the dying person is "patient", whose identity-and purpose are defined largely in terms of the medical treatments and other services being offered - psychotherapy, social welfare, pastoral counseling. The features of the treatment context vary from patient to patient depending on specific medical, psychological, and social characteristics, but for the entire treatment context will influence the needs and concerns of the dying person. The treatment context often produces problems which have to be addressed in therapy. Two aspects of this

context which will be considered are the death awareness and the specific illnesses of patients.

### **Death Awareness**

Glaser and Straus analyzed several patterns of communication between family, medical staff, and dying patients in their important work, "Awareness of Dying" (34). These patterns define the awareness context of the dying person. Each of these patterns is distinguished by the type of communication about the person's condition that takes place between the patient and significant others. Four patterns can be identified - closed awareness, suspected awareness, mutual pretense, and open awareness.

- \* In the closed awareness context others know the patient is dying, but the patient does not.  
For example, the parents of a terminally ill child may pretend that the child will be getting out of the hospital soon, even though they know it will never happen. Parents may play this game to "protect" the child and to try to maintain their own denial.
- \* Suspected awareness exists when others try to deceive the patient about the terminal condition, even when the patient suspects the truth.  
The dialogue below from an interview with two nurses from Glaser and Strauss' book shows the working of suspected awareness in a hospitalized patient.
  - First Nurse: A stern face, you don't have to communicate very much verbally, you put things short and formal ... Yes, very much the nurse.
  - Second Nurse: Be tender but don't...
  - First Nurse: Sort of distant, sort of sweet.
  - Second Nurse: Talk about everything but the condition of the patient.
  - First Nurse: And if you do communicate with them, when you are not too much the nurse, you could talk about all kinds of other things, you know, carefully circling the question of death.
- \* The pattern of mutual pretense is one in which the patient and others have struck a "silent bargain" to pretend that the patient is not dying, even though everyone knows the truth. The dialogue below, also from Glaser and Strauss, illustrates such a context between a nurse and patient.

Interviewer (I): Did he talk about his cancer or his dying?

Nurse (N): Well, no, he never talked about it. I never heard him use the word cancer.

I: Did he indicate that he knew he was dying?

N: Well, I got that impression, yes ... It wasn't really openly, but I think the day that his roommate said he should get up and start walking, I felt that he was a little bit antagonistic. He said what his condition was, that he felt very, very ill that moment.

I: He never talked about leaving the hospital?

N: Never.

I: Did he talk about his future at all.

N: Not a thing. I never heard a word.

I: You said yesterday that he was more or less isolated, because the nurses felt that he was hosted. But they have dealt with patients like this many times. You said they stayed away from him.

N: Well, I think at the very end. You see this is what I meant by isolation-we don't communicate with them.

\* The healthiest pattern is open awareness in which both patient and others acknowledge *and* openly discuss the facts of dying. From a therapeutic stance this is the ideal awareness context and a goal of therapy. Open awareness is not necessarily easy to attain, and attempts to establish this type of relationship may prematurely overwhelm the defenses of the dying person and provoke significant emotional distress. There are many advantages of this open awareness for the patient *and* significant others in the treatment context. Patients and their families can benefit by honest sharing of their experiences regarding death and can prepare themselves more fully for it. Also, the patient is able to make plans and arrangements necessitated by death, e.g., funeral plans, writing a will.

### **Specific Illnesses**

In considering the treatment context of the dying person one factor of fundamental importance is the specific disease from which the patient suffers. Specific terminal illnesses create unique medical, psychological, and social problems for patients. Though there are obviously many diseases which kill people, only a few have received special attention by those working with the dying. Three diseases and their implications for psychotherapy will be discussed here: cancer, Alzheimer's disease, and AIDS.

**Cancer.** Therapists have attended to cancer victims more than any other terminally ill group. Some of the features of terminal cancer which set it apart from other illnesses are its prolonged course, periods of remission, and its stigma (35, 36). Because cancer may be a progressively debilitating disease, the cancer victim can anticipate a long and often painful struggle, associated with aversive medical treatments. For many cancer patients the disease involves a rollercoaster ride from remission to relapse, which is enormously stressful.

Therapists working with cancer patients will focus on the cycle of optimism and despair which accompanies changes in the symptoms of the disease. In addition there are stress and pain management techniques that are helpful in enabling patients to get through the more noxious periods of medical treatment, e.g., chemotherapy. Behavioral therapy techniques such as desensitization and relaxation training have been useful to help cancer patients learn to control the anticipatory stress and nausea related to chemotherapy. (37)

**Alzheimer's Disease.** This is a degenerative brain disease which presents a major health problem for the elderly. The combined physical and psychological effects of this

disease are quite devastating, and taken in conjunction with the normal problems of old age, it creates a host of therapeutic needs for the victims and their families. In the early stages patients and family members benefit by education in the nature of the disease so they can anticipate and better cope with the changes to come, in particular the emotional and cognitive impairments of the patient. With its advance the patient experiences severe dementia, and the focus of therapy shifts more to helping family members manage the patient as effectively as possible, assuming they are in the role of caretaker (38).

Even though there is at this time no cure for Alzheimer's, it is possible to address in therapy the patient's secondary symptoms and their consequences in order to assist the person in adjusting to the disease. Three kinds of issues are of major concern in treatment of the Alzheimer's patient:

- \* Painful Self-Awareness. The emotional reactions of the patient to the physical and psychological debilitation due to the disease may include anxiety, depression, and hostility.
- \* Self-Incapacitation. Numerous self-harming consequences may result from the progressive deterioration, such as careless behavior (e.g., falling down), malnutrition, and self-neglect.
- \* Over stimulation. With reduced stress tolerance capacities and coping ability the Alzheimer's victim may be more easily overwhelmed by tensions and irritations of everyday life. (39)

**AIDS.** The past few years have seen an enormous amount of interest in AIDS (acquired immune deficiency syndrome). Some predictions indicate that AIDS will reach epidemic proportions in the next 20 years. For now though mental health professionals have begun to examine the specific therapeutic needs of AIDS victims. As great as the stigma of cancer may be, it pales in comparison with the stigma of AIDS. Several reasons for this stigmatization are apparent. It is primarily transmitted through intimate sexual contact and sharing of needles by intravenous drug users. The prevalence of AIDS in homosexuals, prostitutes, and drug abusers gives it an association with "deviant" sexuality and antisocial behavior.

Aside from its association with groups who are negatively perceived, the disease is typically fatal, thus allowing little or no hope for recovery on the part of victims. For now at least, a diagnosis of AIDS is equivalent to a death sentence, and the fear generated by this disease among the public has often been turned against its victims and those in high AIDS-risk groups.

Where most other terminally ill patients are pitied, AIDS victims are often shunned, rejected, and met with open hostility, even by those family members and friends who are most needed by the patient.

Presently, the single largest risk group for AIDS is homosexual men, and consequently much of the therapeutic work has focused on the needs of this group. Guilt, shame and fear of recriminations from others are common emotional reactions presented by the gay patient. These feelings are sometimes justified in light of the responses of family and hospital staff. Therapists can work to help AIDS victims openly express their fears and to manage the emotional distress produced by the disease. (40, 41, 42)

## CONCLUSIONS

### What Can Psychotherapy Offer the Dying Person?

Basically psychotherapy offers the dying person much the same that it offers anyone - a supportive relationship in which the individual has opportunities to work on significant personal concerns. The unique life situation of the dying person places limits on the process of therapy and demands greater modesty on the part of therapists regarding possible outcomes. Regardless of theoretical orientations therapists working with dying patients rely first and foremost on communication. Therapy is best used as a forum for exchanging information, educating, expressing fears, and discussing needs.

### What are the Goals of Therapy with Dying Patients?

The major goals of therapy with the dying patient can be summarized in a few simple statements.

1. To allow open communication with patients regarding their conditions, and to provide honest, factual information about those conditions.
2. To facilitate the expression of important emotions and to help patients learn to manage these emotions as well possible under the circumstances.
3. To provide a relationship in which patients can experience support in the confrontation with death.
4. To intervene between patients and other significant people such as family, friends, and medical staff.

The fundamental purpose of psychotherapy for the dying person is best described by Avery Weisman, who proposes that therapy should help patients to participate in "an appropriate death", rather than having an "appropriated death" thrust at them.

"An appropriate death is one that would be acceptable to the patient; a death that might be chosen had there been a choice." (5)

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