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Art Therapy with the Terminally Ill: A Guide for the Art Therapist Working with the Terminally Ill Patient

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ART THERAPY WITH THE TERMINALLY ILL

A GUIDE FOR THE ART THERAPIST WORKING WITH THE TERMINALLY ILL PATIENT

Submitted in partial fulfillment of
the requirements for the degree of
Master of Arts in Art Therapy
The Lindenwood Colleges

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April, 1980

There is destiny that

Makes us brothers.

None goes his way alone.

All that we send into the

Lives of others

Comes back into our own.

Edwin Markham

WITH LOVE AND RESPECT TO

Violet, Charlene, Gladys and Countless Others
who, through their living and their dying
have shown me that, indeed, the circle remains unbroken.

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F O R W A R D

When I first entered into my art therapy studies, my major concern was that my therapeutic endeavors achieve one major goal -- improving the quality of life of those patients with whom I came into contact. At that time, I had no interest in working with terminally ill patients. During the course of my studies, a friend came to me suggesting my involvement in a thanatology program. Hesitantly, I attended initial training sessions. I soon came to realize the need for improved care of the terminally ill, indeed, for improved quality of life for the terminally ill.

Thanatology training (education and training for work with the dying and their families) is complicated. Not only does the subject matter affect each individual to the very core of his being, but working with the terminally ill is a continual, ongoing process. There is very much to be learned, much to be integrated and many fears to be overcome. An individual who wishes to become involved in art therapy with the terminally ill must first become knowledgeable of what dying is all about.

The purpose of this paper is to present, in summary form, what I feel is basic information for those art therapists

who plan to work with the terminally ill. It certainly does not cover all aspects of working with the terminally ill; it would be difficult to cover all important information in one paper or even one book. The information presented here is based on thanatology training programs I have been involved with, on specialized workshops I have attended, on review of literature available on the subject of care of the terminally ill, and on my personal experience in working with terminal patients in hospitals, hospices, and home care settings. It is my hope that this paper will provide a workable basis for art therapists who plan to work with the terminally ill, art therapists who may not have access to specialized thanatology training programs in their particular area. No specialized programs exist for the training of art therapists planning to work with terminally ill patients. Consequently, art therapists must currently rely on thanatology programs for generalized training.

As a group, art therapists have great gifts of talent, and understanding with which to counsel and assist terminally ill patients. Those qualities, combined with their imagination and the art processes, may allow dying individuals to realize and appreciate the truly unique patterns of their lives.

INTRODUCTION TO WORKING WITH THE TERMINALLY ILL

> "Death is not like a person. It is rather a presence. But one may also choose to say that it is nothing and yet it is everything. One will be right on every count. Death is whatever one wishes."
>
> Carlos Castenada
> Journey to Ixtlan:
> The Lessons of Don Juan

More than anyone else, Elisabeth Kubler-Ross has in the last ten years made the general public aware of the needs of the dying. Her books and articles have focused not only on the emotional stages surrounding death, but also on the support needs of the dying individual and that individual's family.

What has resulted from Kubler-Ross' work is a far better understanding of the death process and the patient's need and right for dignity in his or her death.* These needs have not only been realized, but action has been taken across the country toward meeting those needs. Hospice organizations have sprung up, imitating the work of Cicely Saunders, et. al., in England.

While only a few years ago it would have been

*See Appendix for the Patient's Bill of Rights.

unacceptable in most parts of the United States for a person to die at home, the practice of allowing terminally ill individuals to continue living and subsequently die in the peace and dignity of their own homes is growing. Also growing is the realization by the staff of many hospitals providing care for the terminally ill of the special needs of these patients and their families.* Many hospitals are not only beginning to provide special units for terminally ill patients, but are training their personnel to be better equipped to deal with the uniqueness of the terminally ill. Efforts are being made to reach even the physicians (who sometimes have the greatest difficulty dealing with death) in order that they may become more comfortable with the dying and their processes, and thereby better serve their patients.

Kubler-Ross detailed five steps in the dying process which she feels most dying patients go through. Some persons do not go through the stages in the order detailed by Kubler-Ross, and others do not ever reach the final stages. The serving purpose of her outline

*Medical Economics (1980) indicates that while hospices were introduced to the United States only six years ago, hospice programs are spreading rapidly. In the United States, there are now more than 210 programs, most of them hospital-based, offering some form of specialized care for the terminally ill.

of stages is to allow better understanding of the dying person and a basis from which the public can begin their understanding and/or acceptance of the dying process. The stages described by Kubler-Ross (1969) are as follows:

1st Stage - Denial and Isolation

In this stage the patient denies his terminal illness and his impending death. This is usually a temporary defense and only about 4 in 500 terminally ill patients (or less than 1%) remain in this stage until their death. Denial is a defense mechanism whereby the patient avoids facing his imminent death.

2nd Stage - Anger

In this stage the patient is angry, irritable and critical. Kubler-Ross (1969) noted that this stage of anger is very difficult to cope with from the point of view of family and staff. The reason for this is the fact that the patient's anger is displaced in all directions and projected onto the environment at times almost at random. It is important at this stage to allow the patient expression of his anger, even irrational anger.

3rd Stage - Bargaining

In this stage the patient entertains the idea of bargaining, making promises to God, to his family, to himself, in order to prolong his life or to eliminate his terminal cancer. Although less angry, the patient is typically agitated during this period.

4th Stage - Depression

In this stage, the patient reaches a level of no longer being able to deny or "laugh off" his symptoms and his impending death. The patient is experiencing preparatory grief, and is beginning to separate himself from his environment. Companionship is very important in this stage - the company of a caring person who will not tell the patient not to be sad.

5th Stage - Acceptance

In this stage the patient has achieved an acceptance of his impending death and is no longer depressed or angry. He has reached a reluctant stage of inner and outer peace or resolution. The patient's primary need during this stage is, according to Kubler-Ross (1969) "to live to the end with dignity."

During the course of these steps, an individual can remain fixated, for example, in the angry stage (Stage 2) or depressed stage (Stage 4). Physicians, family and loved ones may become concerned with the psychological state of the patient. A psychiatrist or a chaplain may be called in to see the patient. Psychiatric treatment is best sought from trained therapists or counselors who are experienced in counseling the terminally ill. In order for the therapist to assist the patient achieve a better psychological state, that therapist must be familiar with the emotional states of the death process (as defined by Kubler-Ross) and with counseling theory for working with both terminal patients and their families.

THE MEANING AND USE OF ART THERAPY

WITH THE TERMINALLY ILL

> Art therapy provides the opportunity for non-verbal expression and communication. Within the field there are two major approaches. The use of art as therapy implies that the creative process can be a means both of reconciling emotional conflicts and of fostering self-awareness and personal growth. When using art as a vehicle for psychotherapy, both the product and associative references may be used in an effort to help the individual find a more compatible relationship between his inner and outer worlds.
>
> Art therapy like art education may teach technique and media skills. When art is used as therapy, the instruction provides a vehicle for self-expression, communication and growth. Less product-oriented, the art therapist is more concerned with the individual's inner experience. Process, form, content and/or associations become important for what each reflects about personality development, personality traits and the unconscious.
>
> (Proceedings of the American Art Therapy Association)

In art therapy with other populations (such as psychiatric, substance abuse, family therapy), the therapist in many cases confronts the patient with the content of the art. Repressed psychological material is often apparent in the patient's art, and it becomes the therapist's responsibility to assist the patient in recognizing repressed emotions and defense mechanisms and to see ways of better dealing with existing problems in the patient's life.

Art therapy with the terminally ill is not concerned with interpretation of the patient's art nor is it the role of the therapist to confront the patient with inappropriate defense mechanisms or behavior. Attempts to modify or remove inappropriate behaviors* during the last weeks or months of an individual's life may, indeed, have a negative effect upon the patient. Just as an individual's defense mechanisms may allow that individual to function, a terminally ill patient's defense mechanisms may keep the patient from prematurely giving up hope and/or dying.

Art therapy with the terminally ill is meant to be a non-analytic art experience and an experience meant to be positive. It is also an attempt to assist the patient in coping with the patient's anger, denial or depression and to help the patient come to a better acceptance of himself and his impending death. This can be effected only with minimum threat and maximum enthusiasm and caring on the part of the therapist.

The therapist should, idealistically, be primarily concerned with the quality of life of the terminal patient, and strive toward giving psychological comfort

*For a different point of view, see Whitman and Lukes (1975) for outlining behavior modification techniques for terminally ill patients.

rather than confrontation of existing inner conflict.

Guthrie (1979) quotes Kubler-Ross as encouraging "professionals working with the terminally ill to give the patient a chance to talk about his or her feelings, to work with the patient and his family to maintain near-normal relationships as much as possible, and to control the patient's pain so that he can live the last days or months as fully as possible."

One thing that the therapist must remember: The patient need not recognize, deal with or resolve existing inner conflict before he dies. A patient need not die in a state of good psychological health. It is important that the patient achieve some level of self-acceptance and acceptance of his death before it occurs and that the patient be allowed to share communication of concerns and receive assurance that his particular needs will be met.

From my experience in working with terminally ill patients, I have found that art therapy and its processes may indeed facilitate the following:

1. Release or expression of emotions and tensions.
2. Acceptance of the death process.
3. Life review - which may allow for better appreciation of self, along with past life.
4. Communication, friendship and caring.
5. Reduction or control of pain through the use of art combined with imagery and visualization.

There has not been an abundance of art therapy done with terminally ill patients.* When used, it has been used as a tool not only to cope with evident anger, denial, depression and other emotions involved in the death process,** but also to reveal the hidden unexpressed emotions of the terminally ill.*** Dilley (1971) said that "the use of the visual dimension in counseling provides greater insight into the actual depicting of a problem, has more permanence than verbal interaction, and has the potential to minimize the ambiguity of a message."

*Art therapists known to the author who have worked with terminally ill and/or presented documentation of their work include: Nola Kurtz, Center for the Healing Arts, Los Angeles, CA; Jenny S. Effler and Jane E. Sestak, Cleveland Clinic Foundation, Cleveland, OH; Ruth Obernbreit, Jewish Community Services of Long Island, NY; Linda B. Sibley, Pratt Art Therapy Program, New York, NY; Carol F. Perkins, Louisville General Hospital, KY; Gerald G. Jampolsky, Center for Attitudinal Healing, Tiburon, CA.

**As defined by Kubler-Ross (1969).

***See Kubler-Ross (1978) and Bach (1966).

Aside from the immediate thought that art therapy might prove valuable in working with the terminally ill or particularly suited to terminally ill children and adolescents, art therapy may also be very valuable in working with patients unable to speak. Art therapy as a non-verbal form of communication may be used with deaf patients, with those patients who have lost the ability to speak or who have speech disorders (such as aphasics), patients with cancers affecting their vocal chords, those patients on respiratory machines or those patients whose primary language is other than English; that is, all patients who, for one reason or another, are not able to verbalize their concerns and fears, are good cadidates for art therapy.

Also not to be overlooked are those patients who become so removed or withdrawn from the environment around them, either at home or in the hospital, that they seemingly cannot be reached through language. To these individuals, art can seem less threatening than verbal communication and be not only a means of communication, but also a means for release of energy and a possible avenue toward acceptance of both their illness and their environment.

Long-term art therapy with the terminally ill affords the therapist both a greater opportunity to experience the stages of dying with the patient and affords a greater understanding of that individual's dying process (long-term art therapy is also subject to the therapist's over-involvement with the terminal patient and subsequent problems therein).

Few therapists are afforded the opportunity to work with terminal patients on a long-term basis. When diagnosis of a terminal illness is made, very few physicians refer their patients to a psychiatrist or counselor or therapist of any kind.* Consequently, most terminally ill individuals are left to their own measures during the early stages of their disease and dying process.** When the patient is either in the hospital in a crisis-intervention situation or in a hospice or home care situation where the caretaker, family or physician becomes concerned about the patient's emotional state of mind, a therapist may be contacted. Usually this contact is sought by the attending

* Kubler-Ross (1975) has noted that "counseling is more likely to be effective at this stage, shortly after the physician has informed the patient of his condition and before bitterness, anger or depression has taken root too deeply."

**The Community Cancer Control, Los Angeles, Inc., is (seemingly) unique in that its program offers psychosocial counseling and support for patients and families from the initial diagnosis of cancer.

physician through hospital departments such as oncology to social services or psychiatric services, or through home health agencies to staff personnel.

Art therapists thus do not often come into contact with a patient for an interval of time allowing long-term art therapy. However, although not allowing for long-term art therapy, the interval of time remaining for short-term therapy does afford the art therapist time in which dynamic therapy may be conducted -- that therapy during the very last weeks of an individual's life.

An art therapist may get a referral* to see a terminally ill patient on an outpatient basis. Although the patient may be seen at a therapist's office, the art therapist will probably need to see the patient at an outpatient clinic or in the patient's home, or more likely, on an inpatient basis, where the patient will be seen in the patient's hospital or hospice room.

When seen on an inpatient basis, most patients are unable to move from their room to another room such as an art activity room, if indeed there is even one available. Physical limitations of patients, lack

*Freedman, et. al. (1980) found that of all cancer patients referred for psychiatric treatment, depression appeared to be the most common mental disorder found in the cancer patient under age 60 (both sexes), while organic brain syndromes were the most common mental disorder found in the cancer patient over age 60 (both sexes).

of nursing personnel to assist such a move from bed to wheelchair to bed, and the fact that many patients are connected to an assortment of machinery and intravenous equipment accounts for the limitations on patient movement.

With hospitals often crowded, the patient is likely to have at least one roommate. The therapist and patient will find themselves sharing art,* communication and therapy on only a semi-private basis. This is not a desirable condition for either a patient or a therapist to be in, but it is the condition under which art therapy is conducted in many hospices, intensive care wards and oncology wards of hospitals.

While it is important for the art therapist to know and anticipate the environments in which she will work with terminally ill patients, art therapists must have a full understanding of the dying patient and the death process. Accordingly, the art therapist must have empathy and compassion for the patient without being consumed in an envelopment of pity or inappropriate involvement.

*Obernbreit (1979) notes that "the art experience by its very nature is personal and private."

An art therapist would not start therapy with an individual or a group who have a particular psychological problem (such as marital discord, sexual dysfunction, drug abuse, etc.) without prior knowledge and training in that field. Neither should an art therapist or a therapist of any kind begin seeing a terminally ill patient in therapy without receiving some training in thanatology. Each patient is unique. Among the terminally ill population, the uniqueness of each patient is heightened. Each brings with him not only his uniqueness, but a sense of urgency and finality which one cannot help but feel the magnitude of.

The therapist must keep in mind that being involved in art therapy with any individual or any group is an experience, of sorts, in terminality because we are all, every group, every therapist, terinal. There is noe undeniable truth and that is that we will all die someday. Acceptance or denial of this truth and how patients and we as therapists* face and cope with fears of death (or the unknown) tell us much about how individuals respond to their impending death. Accordingly, our expectation of how we would wish to be treated during our own terminal illness should allow us to realize the importance

*Kroft (197-) states that "for some of those who have great difficulty in accepting awareness of their own future death, the chronic disorder of another will create discomfort, anxiety, despair and the desire to flee."

of dignity in death and throughout the dying process.

Feifel (1977) noted that "in the last analysis, all human behavior of consequence is a response to the problem of death," while Hetzler (1974) explored the effect of man's knowledge of his mortality on his behavior. The fact that we all must die can "itself mold the way in which we do live -- to make life more fruitful, more creative, more uncompromising in aspiration, more forceful in performance, and more resourceful in the means toward resolution. The phenomena which enrich life give it purpose, scope, resilience and beauty despite the trauma inherent in contemplating its unknown finality."

Any therapist working with the terminally ill will, with time, realize that a ritual drama of mutual pretense often exists. Glaser and Strauss (1965) define mutual pretense as the situation of both the patient and staff knowing that the patient is dying but pretending otherwise - "when both agree to act as if the patient were going to live." Although the mutual pretense may allow the patient "a measure of dignity and considerable privacy," it does eliminate any possibility of the therapist working with the patient in a psychologically intervening manner.

What can the therapist do when faced with the dilemma of mutual pretense? A therapist can give the patient opportunities to speak of his dying process and death without directly or obviously referring to the topic. But if the patient does not choose to speak of his or her dying, then the pretense will continue. What avenues are then left for the therapist? The therapist may concentrate on expression of emotions, on life review or reminisce with the patient, allowing the patient time to review and/or reminisce about his life, the disappointments and successes, the loves, marriages, children, etc.

Mutual pretense usually collapses* when the patient's physical condition deteriorates to the point of making the maintenance of the pretense either difficult or impossible. According to Glaser and Strauss (1965), "When the patient cannot keep from expressing his increasing pain or his suffering grows to the point that he is kept under heavy sedation, then the enactment of pretense becomes more difficult, especially for him."

As noted, <u>life review</u>, or the remembering and recalling of past life events and concurrent emotions, often

*The term used here is "usually" since some patients never relinquish the ritual of pretense, regardless of physical deterioration.

allowing for improved acceptance of past lifes and, consequently, improved self-esteem, is a tool used by art therapists working with the terminally ill. It is a particularly usable tool when working with patients who employ pretense during the dying process.

Zeigler (1976) in her discussion of life review with the aged through art therapy, speaks of Butler's (1963) interpretation of life review. Zeigler states that

> "Butler sees life review as occurring naturally and arising out of the aged person's need to reexamine and resolve past conflicts in order to restructure present experience in the face of impending death. If this process is successfully completed and past conflicts are resolved, then Butler contends, wisdom and serenity may be attained. If the process is not completed, then despair or psychopathological symptoms may result...."

Butler (1963) states that

> "The life review is a universal mental process characterized by the progressive return to consciousness of past experience, and particularly the resurgence of unresolved conflicts....presumably this process is prompted by the realization of approaching dissolution and death....The life review, as a looking-back process that has been set in motion by looking forward to death, potentially proceeds toward personality reorganization."

Zeigler goes on to state that

> "Life review activity represents a normal and positive adaptational response to impending death....It is normal for old people to talk about their past and such talks are to be encouraged. Second, that the therapist needs to be a sympathetic listener. Third, that the sensitive use of art activity can stimulate the recall of forgotten or repressed material and thereby further the personality reorganization of the life review process. Life review, of course, is not a panacea for all the problems of the aged, but I believe it is worthy of the consideration of all who work with the old. Happier tomorrows for the elderly may well lie in a therapeutic searching of their past."

Much of the art produced by geriatric patients is art of life review, art representative of art produced by terminally ill patients also. This art, labeled as "life review art," is full of family, marriages, past significant life events, including past successes, failures and disappointments.

When asked to represent in art form what the greatest disappointment a terminally ill individual has, they are likely to respond that they were never able to have one last child, never able to take piano lessons, or ballet lessons, never able to devote their younger years to personal endeavors, rather than getting married or becoming employed. Although these individuals

may have, during their lifetimes, experienced major disappointments, during the dying process they often allow themselves to focus on relatively minor disappointments which may be discussed with the therapist, while the major disappointments may not be.

The purpose of life review is straightforward. Through life review, the art therapist hopes to allow patients to see the significance of their lives and the importance of their particular life patterns, therefore realizing that their lives have had a purpose and/or meaning.

Through life review, the therapist attempts to assist the patient in integrating past (and present) life situations and emotions. This sometimes means assisting the patient in completing or finishing situations which in the past were left unfinished.

Keyes (1974) notes that

> "Finishing situations refers to a person's sense of not completing an act. Words unsaid and things undone leave a trace, binding us to the past. Sometimes this involves a psychodrama, acting a fantasy out, finishing an unfinished dream, saying to patients what was not said to them in childhood, saying goodbye to a divorced

> spouse or a dead relative. What was unsaid, withheld, may have been appreciation or resentment."

Keyes (1974) shared one of the art therapy techniques she uses with patients (although not necessarily terminal patients). It bears repeating here, as one of the many varied forms of techniques used in the life review process.

> Materials you will need: A large piece of paper at least 24" x 36", poster paints, felt-tip pens, or charcoal.
>
> Imagine that this paper represents the whole of your lifetime, the beginning, the now, the future, and the end. First sit quietly for a few minutes, then fill it however you choose. Don't expect anything, or try, or analyze, just allow your mind to be quiet, to let happen what will by simply holding the thought: This is my lifetime.
>
> When you have finished be aware of the quality of your breathing and how your body feels, and how it felt to be totally abosrbed withthe making. Where do you feel the most excitement? What did you discover? What do you want to share?

Crosson (1976) in discussion of the lack of spontaneity in geriatric patients, noted that she felt it to be a therapeutic success if a geriatric patient "merely picked up a crayon or chalk." Crosson also notes that

"many of the geriatric patients in a nursing home have not handled paints or colors since elementary school, and have no intention of starting now." One can easily relate the situation of the geriatric patient to that of the terminally ill patient.

Although there may be a need for art activity and consequent release and expression of emotions, there is also a need not to force a patient into art activity or art therapy. And although reinforcement from an art activity or art therapy is best achieved if the art is finished or continued to termination, completion should not be forced. Positive reinforcement does come from the completion of art therapy sessions or an art activity. Such completion can be an ego boost and may provide emotional and, in some cases, physical promotion.

However, Crosson (1974) states, "The art therapist working with ill, old people in a nursing home must learn to be satisfied with limited gains. If she can see improved perception in a patient's artwork, no matter how simple; if she can see an increase in self-esteem, no matter how temporarily; or if she can see an expression of beauty

or representation of an important facet of the life of the individual, her work can be said to be successful."

ART FORMS FOR CREATIVE EXPRESSION

Mass (1979) noted that

> "Everyone, especially those in sterile institutions, needs the opportunity for creative expression. Exposing people to the creative process provides them with a way to express themselves, which leads to insights and stimulates personal growth. Appropriate creative activity can help both psychological and physical development." Mass (1976) had previously noted that "certain media and techniques are better for certain people in helping them achieve their therapeutic goals."

All art therapists use a variety of art media, often using specific art media with certain patient populations. There are art media that are better adaptable to use by art therapists working with the terminally ill. Art media used must be those which a terminally ill patient (often hospitalized) can work with without major difficulty. Another consideration is past experience in or preference for certain art media. Given the usual time, environmental or physical limitations, prior knowledge of an art media may facilitate the therapy, with the patient being less reluctant (less fearful) to engage in the art activity.

With art media, the art therapist needs to be somewhat flexible*and needs to be able to instruct the patient as to how to use the art medium.

*Some art therapists do retain the position that specific art media should be used with specific populations, such as only certain art forms with depressed patients, only certain art forms with anxious patients, etc. For clarification, see H. Landgarten (unpublished).

The art media that are better adaptable to use by art therapists working with the terminally ill are as follows:

Simple sketching, drawing or scribbling with pencil, ink pen, crayons or felt-tip pens. Felt-tip pens and crayons afford a multitude of color and, consequently, allow representation of a wider range of emotions.

Painting (oil, acrylics or watercolor) may be used with adequate trays, etc., when the patient is able to sit up. Acrylics or watercolors may dry and/or be completed in less time than oil paintings and may allow a terminally ill patient completion of a painting (and expression) before death or before the patient is too ill or incapacitated to paint.

Collage (either paper or mixed media) is an excellent alternative for the patient who is reluctant to "start working from scratch" and who feigns non-artistic talent yet has a need for a release of emotion or an exchange of communication. Collages can also be completed in less time than most paintings. Paper collages also allow the patient to rely on the emotions

depicted in magazine pictures or mixed media to convey his own emotions.

Newton (1976) states that "making a collage is an easy way for people to express a 'who am I' impression of themselves. One need not have artistic talent in order to make a collage; by going through a few magazines, clients can pick our words and pictures that express something about themselves." Terminally ill patients who themselves are often feeling fragmented, can benefit from organizing fragmented pieces of paper, magazine pictures or odds and ends into a creative collage or sculpture.

Group murals (collages or painting) according to Mass (1976) "give a good opportunity for social interaction. Working on a large area encourages more physical involvement. On display, a mural changes the environment in a dramatic way because of the noticeable group effort and large size."

Working with clay, either as a means in itself (such as working with the clay to release emotions) or as a means to an end (sculpture) is an excellent therapeutic

tool, allowing the patient to ventilate angry and hostile feelings felt toward his illness, his medical treatment, doctor, hospital, staff, etc. This activity, however, must be reserved for patients with adequate strength left (the therapist must always remember to not allow the patient to overtire himself). Most patients hospitalized on oncology wards do not have many days where they feel strong enough to attempt much activity, particularly strenuous activity, or days when they either are not experiencing side effects such as nausea, from chemotherapy or radiation.

As the patient produces art, the art therapist examines the art carefully. The pictures created tell much about how the patient is feeling about himself, about his illness, and about his past life, along with his hopes and fears.

After the art is completed, it is important that the therapist and the patient discuss the art. Although the art is often revealing in itself, often the patient benefits from discussing his art and its meaning, and the therapist learns much about his patient. If the patient is allowed to keep the art, and is able to review the art, he may gain additional insight from reviewing it.

Jaffe (1980) states that "such drawings continually help people discover new aspects of themselves."

While art produced in other patient populations is often retained by the therapist, a piece produced during an art therapy session or art activity becomes the property of the patient. Mass (1979) in discussing the final product of a session states

> "The finished piece becomes something for which the patient can decide the destiny. Most handicapped, institutionalized people lose their options to make even simple decisions. The art piece becomes theirs to destroy, keep or give to someone. If the decision is made to give it as a gift, it helps reverse the patient's role as a receiver of attention and services."

STRESSES EXPERIENCED BY THE TERMINALLY ILL ALONG WITH SUICIDAL IDEATION AND RISK

As every therapist knows, mood swings are normal to the general public. Every individual has them to a greater or lesser degree. This seems even more true of the terminally ill. Regardless of the overall state that the patient is in, that patient may be cheerful one day and withdrawn the next, just as that patient may be coherent one day and incoherent the next. These states are due not only to psychological implications of the dying process, but also to physiological reasons such as pain, medication, medical treatment of the day, etc.

Accordingly, a patient may be willing and able to engage in an art therapy session one day and unwilling or unable to do so the next. A therapist's willingness to be flexible and understanding of each daily experience is essential. Daily major fluctuations in mood and coherence may actually allow the therapist to better know his patient and, therefore, better able to aid or assist that patient attain a death with dignity.

There is one unmistakable fact - death anxiety is very stressful and exists in every patient who has been diagnosed terminal.

Since it is often difficult for individuals to actually verbalize their fears, art therapy is an ideal tool for working through fears. Levitt and Guralnick (1979) listed fears that are most often expressed by the dying patient. These are all fears which the therapist needs to be aware of.

What fears are most often expressed by the dying patient? Most dying patients fear mutilation and pain, and fear for the welfare of their family. Other fears, in no particular order are:

Ceasing to be
Having to give up a pleasurable life
Having to leave a profitable business or profession
Leaving unsettled an estate, or will, or insurance
Causing the survivors great medical expense
Losing every relationship in life
Facing the unknown
Leaving behind unfinished work
Becoming dependent on others
Losing control of the body and possibly even the mind
Becoming a nuisance to others
Leaving life before having enjoyed it
Parting with family and friends
Dying alone without family or friends nearby

Coping with a diseased body

Appearing undignified because of the ravages of the disease

Behaving badly as death approaches

Being the last witness, the last link, to a particular event, or society or person

Relinquishing a body or a personality that gave and received pleasure

Losing the future and not being able to witness what is yet to come

Facing the possibility of an afterlife

Being judged after death and held accountable

Having no time to apologize for past arguments and to reconcile differences

Having been an indifferent churchgoer or a nonbeliever

Dying over a long period of time

Exploration of these fears with the patient affords the opportunity for frank discussion and, consequently, alleviation of the patient's stress. For instance, the art therapist might attempt to explore the patient's fear of losing every relationship he has or facing the possibility or non-possibility of an afterlife. Those therapists finding themselves in a situation of pretense* with a patient should attempt to discuss such fears as having to give up a profitable business or

*See previous discussion on mutual pretense.

pleasurable occupation, or the fear of becoming dependent on others. If the therapist is able to assist the patient in discussing his illness, and incapacities, then the possibility of the patient relinquishing the pretense is more attainable.

The purpose of discussing a patient's fears is not to terminate a patient's pretense, however, but to lower the patient's level of stress either verbally through discussion, non-verbally through art or through a combination of both.

How does the therapist recognize stress in the terminal patient? Brotman Medical Center's Thanatology Program (1980) outlined symptoms of stress in the patient, the patient's family, and in the therapist working with the terminally ill. These symptoms are as follows:

Patient-Symptoms of Stress

1. Easily fatigued
2. Withdrawn and depressed
3. Avoiding conversation
4. Giggling and inappropriate humor or responses

Family-Symptoms of Stress

1. Unwilling to help patient
2. Overwhelming the patient
3. Fatigued appearance
4. Frequent episodes of crying
5. Denial of stress
6. Difficulty coping with needs

Therapist or Volunteer-Symptoms of Stress*

1. Uneasiness in working with the patient or family
2. Frustration with lack of time
3. Sense of guilt when unable to visit the patient or family
4. Feelings of discomfort when unable to communicate with the patient or family

In dealing with the general public, the art therapist will sometimes see indications in a patient's art that the patient is suicidal. The therapist may even be told so by the patient himself, although the verbalization is oftentimes not made by the patient until the patient is confronted by the therapist with the evidence from his or her art.

When suicidal representation is evident, the therapist should (1) be frank with the patient; (2) discuss concerns of the patient which are causing him to feel suicidal; or (4) try to be of assistance. This may mean involvement with the family, requesting that medication or pain control be checked by the patient's

*Personal management of stress and other negative manifestations found in caretakers of the terminally ill will be discussed in a later chapter.

physician or nurse, etc. It is important that the patient's doctor and primary caregiver be aware of the patient's suicidal potential. Approach the physician and/or primary caregiver with not only your suspicions of the patient's suicidal intent, but also with the patient's art and theory regarding suicidal art.

For the terminally ill, suicide is one way of coping with the frustration and pain of a terminal disease. While suicide attempts among terminally ill patients are rare, Kubler-Ross (1974) notes that, "More often suicide attempts are made during the later stages of illness when the patients are less able to care for themselves, or when the pain of the terminal disease becomes unbearable."

Levitt and Guralnick (1979) indicate greater numbers of attempted suicides by individuals "suffering from severe anxiety, having little or no tolerance for pain or enjoying no emotional support from family or friends."

Weisman (1979) notes that suicide attempts, whether completed or not, occurred "just as often during remission and with tumors of low malignancy, and with patients

suffering from severe symptoms and disabilities." Weisman (1979) goes on to state that the "relation of coping, cancer, and suicide remains an intriguing problem."

Suicidal ideation in a patient brings up two questions for the therapist:

(1) What is the risk that the patient will actually attempt suicide?
(2) What can the therapist do to reduce the suicide risk and better help the patient cope with his terminal disease?

Kubler-Ross (1975) has outlined what she feels to be major categories of suicidal risk that patients fall into. They are as follows:

1. Those who have a strong need to be in control of everything and everybody.
2. Those who are told cruelly that they have a malignancy and there is nothing else that can be done because the patient came too late for help.
3. Patients in the dialysis programs and/or

potential organ-transplant patients who have been given too much hope and an unrealistic assessment of their condition have a tendency to suddenly give up hope and often die of what we call a "passive suicide."*

4. Those patients who are neglected, isolated and deserted, and receive inadequate medical, emotional or spiritual help in this crisis.**
5. Those individuals who are usually not conventionally religious but have accepted their finiteness and would rather shorten the process of dying than linger on for another few weeks or months in what they regard as useless suffering.

*Passive suicide refers to behavior detrimental to the self yet not overtly suicidal in nature, such as not taking proper medication or not following prescribed medical or activity regimes.

**Perhaps those individuals receiving inadequate financial help should also be included here.

In contrast, Weisman (1979) profiles characteristics of high suicide risk in depth. These characteristics are as follows:

HIGH RISK PATIENT PROFILE

Personality:	Low ego strength, high anxiety
	Pessimistic
Past History:	Marital problems, if married
	Living alone
	Lower socioeconomic status
	Alcohol abuse
	Infrequent church attendance
	Multiproblem family origin
	Psychiatric treatment
	Suicidal ideation at times
Physical Status:	Advanced staging
	More reported symptoms
Plight:	More problems of all types
	Expects and receives little help
	Sees physicians as less helpful or concerned
Performance:	Suppression and passivity
	Fatalistic submission
	Isolation and withdrawal
	Blames others
	Blames self
	Feels like giving up
	Poorer resolutions

Those involved in art therapy with family members of terminally ill patients should realize the implications of suicide. Kubler-Ross (1974) has noted that "because of the nature of the death of this loved person, there are usually a lot of additional guilt feelings and regrets. It often requires professional help for the family to reach the stage of peace and acceptance. This grief will naturally last much longer than if the

person had died of natural causes."* Consequently, these family members will require prolonged therapy and bereavement counseling.

The art therapist, or anyone working with the terminally ill, should know that the quality of life, not life itself, is what care of the terminally ill is concerned with. The ethical issues surrounding a possible suicide are, therefore, more complicated and need to be dealt with on an individual basis. For the therapist, this may entail sharing a confidence with a professional co-worker and/or someone who has experience working with suicidal terminally ill patients.

*This state of prolonged and exaggerated grief for loved ones and/or parents who have committed suicide is evidenced by emotional states found in a large number of psychiatric patients and is an area in which research is still needed.

ART THERAPY AND GRIEF COUNSELING WITH THE PATIENT'S FAMILY

> "...I went alone to the cemetery...I saw the small rectangular maker with her name and dates. I sat down at the edge of the raised family grave. There were only a few people scattered across the cemetery and none nearby. Without warning, I began to sob. My tears came in great uncontrollable torrents. And when I put flowers on the sand before her stone, she was not there to know. There was no one there but me."
>
> (Rodman, 1977)

While working with the terminally ill, the therapist comes into contact with family members who are grieving the impending loss of their loved ones. Whether these individuals are husbands, wives, children of the terminally ill, or parents of dying children, many require not only counseling prior to the death of their loved one, but also bereavement counseling following the patient's death.*

Hetzler (1974) defines bereavement as "a diminishment in being which brings with it anxiety, grief, often illness, not only because of the new emptiness, but because of fear that this void will never be even partially filled."

During the patient's illness, the family has been

*Although this paper does not deal in depth with counseling of family members of the terminally ill, nor bereavement counseling, therapists should be aware of such needs. Grief and/or bereavement counseling is a vital part of thanatology training and is an area in which additional work and research is needed.

living under great stress - under a constant threat or fear of losing their loved one. Shubin (1978) notes that "patients and their families try to handle the stresses in three major ways - by being open with each other about the illness and future, by denying its seriousness, or by alternating between acceptance and denial." The art therapist may work with family members during any of these phases, although it is more difficult to work with the family member during a state of denial. In this state, as with the terminal patient who pretends not to be aware of his death process, it is useful to work with family members on their fears or stresses surrounding the patient's illness and incapacities, rather than directly focus on the imminent loss of their loved one. Thereafter, the possibility becomes greater of the survivor discussing his or her feelings regarding the impending death.

Family members often seen for grief or bereavement counseling are spouses, children (which may mean young children, adolescents or adults) and parents. Art therapy may be utilized for all populations, but is perhaps most easily used with children and adolescents who, on a more regular basis, use art forms to express themselves. Indeed art therapy may be the best form

of therapy for children and adolescents who often have difficulty verbally expressing their grief. McDonnell (1979) indicates that a child's response to such a stressful event may be "anxiety, fear, regression, withdrawal, or oppositional behavior." Art therapy may be used to establish both non-verbal and verbal communication.

Rosenbaum and Rosenbaum (1980) state that:

> "Children of cancer patients often need special understanding. Absence of a parent during hospitalization and the fatigue following treatment may cause children to feel neglected and lost. Children may also feel they caused the illness; this misconception must be corrected quickly. Reassurance from other family members is important for children to realize they are still loved. Adolescents are particularly vulnerable to stress, as they may be asked to assume a supportive role, to approximate a spouse. If this responsibility is beyond the capabilities of the adolescent, he may rebel by not making hospital visits or by excessive drinking or drug use. Adolescents are adults - up to a point - but they still require the reassurance and comfort routinely given to younger children."

Perhaps no counseling or therapy is as difficult as that counseling of the parents who have experienced the death of a child.

The greatest of all griefs, the greatest of bereavement, is that bereavement experienced by the parents of deceased children. The death of a child is frequently

called the "ultimate tragedy." Any parent will be able to relate to this statement. Not only is the waste of life apparent since the child has not lived his full potential, but parents do place their futures and their own aspirations in their children. The death of a child signifies not only a tragic waste, but the end to a portion of the parents' own goals and ambitions.

Schiff (1977) has noted that grief following the death of a child is not automatically cut off after a respectable interval: "It is a long-term anguish." Schiff has also noted that within months following the death of a child, a very high percentage (or an estimate of approximately 90%) of all bereaved couples are in serious marital difficulty. Counseling is needed not only throughout the illness and immediately following the death of the child, but for some period following such a death. The dying child must be discussed by each parent perhaps both individually and as a couple with a therapist equipped to deal with the ethics of death and dying, both during the course of the terminal illness when the parents are facing the prospect of their grief, and subsequent to the death of the child.

Just as there are no specialized training programs for art therapists working with the terminally ill, there are no established guidelines for art therapy with the bereaved. What is available are guidelines for bereavement counseling, guidelines which the art therapist may use and assimilate into their art therapy.

Following is an eleven-point outline for use by therapists involved in grief counseling:

GRIEF COUNSELING

1. Try not to inhibit the expression of appropriate grief.
2. There is no "correct thing to say." If you are genuinely interested and receptive, the family will know.
3. Expect everyone at times to be embarrassed by your presence (including yourself).
4. After expressing conventional expressions of sympathy, speak from the heart.
5. The important thing is for feelings to emerge into consciousness. Not everyone expresses feelings in the same way.
6. Expect to grief with your patients. Communal sorrow reduces isolation.
7. At the earlier stages, taking over tasks and responsibilities is helpful. It frees the person to grieve. It will be most appreciated later.
8. Provide a warm silence into which the person may pour out his feelings. A gentle touch is helpful.

9. Draw in friends and neighbors when possible.

10. Intensity of emotions can be great. Reassurance is the key; it will enhance your relationship.

11. Remember that grief can be shared but that each person must walk the path. They cannot be rushed or pushed.

Jeffrey Stevens, M.D.
(publication unknown)

TRAINING AND MEDICAL ORIENTATION OF THERAPISTS WORKING WITH THE TERMINALLY ILL

> A terminal illness has "consuming, complex, psychological, existential and interpersonal problems inherent in the dying process.... it is every terminally ill patient's right to have access to a trained, experienced counselor whose specialty is to deal with the dying."
>
> (Source unknown)

Training programs for those individuals considering working with the terminally ill are oftentimes available at local hospitals, hospice organizations or local cancer associations. Such organizations are often eager to provide training in the field of thanatology,* oncology and "death and dying." Trained personnel or trained volunteers are needed to assist organizations in their care of the terminally ill. These programs and the experience they provide offer needed academic and practical knowledge for those willing and able to work with the terminal patient.

Art therapists who want to work with the terminally ill and who are unsure about how to begin should check with local hospitals. Hospitals may have oncology wards

*Hetzler (1974) defines thanatology as encompassing "what death, dying, loss, grief and bereavement are all about. By extrapolation, thanatology gives new forms to the dimensions of living, new reinforcement to the purpose of life, deeper feelings of urgency to the atmosphere of being."

with training programs for those who wish to donate their time in a volunteer capacity. Many communities have home care agencies. Many health services providing medical treatment for seriously ill or terminally ill patients are eager for volunteers and particularly eager for those volunteers offering a specialized service such as art therapy. In addition, time spent in a convalescent hospital or a nursing home is also excellent training either prior to or in conjunction with thanatology training, because patients in these facilities are in a pre-terminal stage.

Just as working with the terminally ill is a difficult task, death and dying is not a simple subject. Those working in the area need to know not only the psychological aspects and complications, but the physical aspects and complications of the terminal disease which their patient has.

First of all physical symptoms often seen in the terminally ill are:

Weakness
Thirst
Dysphagia (loss of appetite)
Nausea
Constipation
Bowel obstruction

Dyspnea (labored respiration)
Bronchospasm (tightness in chest)
Incontinence (inability to control bladder)
Anorexia (difficulty in swallowing)
Dry mouth
Confusion
Vomiting
Diarrhea
Decubiti (bedsores)
Cough
Pain*
Open wounds and draining

With terminal illness, there are also implications of physical regimes, catheters, colostomy surgeries and colostomy bags, etc. There are a multitude of medical aspects of terminal illness which anyone working with the terminally ill must be aware of. Many of these medical aspects are not pleasant (for either the patient or the therapist) to cope with and a therapist must be prepared to deal with his or her own difficulties with these aspects before attempting to help a patient deal with them.

How would anyone be able, for example, to work with a young woman who has bowel cancer and has just had a colostomy if that therapist is unfamiliar with the daily necessary regime of colostomy patients or unfamiliar with the consequent emotional factors of the disease and the process? Or if, in fact,

*Since the patient's world oftentimes revolves around his pain medication, commonly referred to as pain control, a therapist must be familiar with this aspect.

familiar with the process, uneasy or unable to deal with these factors herself?*

One of the major drawbacks in working with the terminally ill is the fact that on many days a terminally ill individual does not have the physical strength to be involved in an activity either on an emotional or on a physical level. This condition may often be due to side effects of treatment programs, programs which may include surgery, chemotherapy, radiation therapy, hyperthermia or, more likely, a combination of these modalities.

Since many individuals suffering terminal illness have cancer, it is important to understand what cancer is, to understand treatment programs and to be aware of the consequences for the patient and the therapy.**

*Effler and Sestak (1979) have noted that "the degree to which the art therapist is able to be effective and objective with her patients is partially dependent on her own resolution of the issues confronting her patients....A non-resolution of these issues, personally, may manifest itself in many ways in the work setting."

**Rosenbaum and Rosenbaum (1980) note that "although we speak of cancer as singular, it is not a single disease, but over four hundred different diseases that can originate in any cell or organ in the body."

Levitt and Guralnick (1979) explain cancer as a "misguided cell or cells," as a "growing process gone beserk." What these cells do is grow in defiance of the body's normal growth control mechanisms.

The goal of surgery for cancer treatment is to remove the cancerous growth.* However, if the tumor removed is found to be malignant (rather than noncancerous or benign), the cancer may have spread, or metastasized, to other parts of the body. Consequently, other therapies, such as chemotherapy and radiation, are then warranted in order to either control or eradicate the disease from other parts of the body, other than the original site of the tumor.

Chemotherapy is drug treatment (with a wide variety of chemicals) that changes the lymph cells. However, because of the powerfulness of the drugs, while destroying the cancerous or unhealthy cells, the chemotherapy also destroys healthy cells. Van Scoy-Mosher (unpublished) notes that the "toxicity of a drug -- the damage it does to normal cells and tissues -- depends upon a variety of factors, including the type of drug, the dose, and the way it is administered. Therefore, it is difficult to predict precisely how a patient will

*Rosenbaum and Rosenbaum (1980) again note that surgery is sometimes used as a non-curative procedure -- for instance, to reduce pain, or to alleviate crisis, such

respond. Oncologists try to balance the unpleasantness of temporary side effects against the potential for longer-term benefit."

Mild discomfort caused when chemotherapy is given intravenously may be experienced, but chemotherapy may also cause a number of immediate side effects. Levitt and Guralnick (1979) list these side effects as

> "...nausea, vomiting and diarrhea, dryness and soreness of the mouth which may produce mouth sores, loss of hair, improper control on infection, bruising, fatigue, weakness, loss of appetite, anorexia, discoloration of the skin and skin rashes, irregular menstral cycles and sterility in both men and women...."

Radiation therapy is the use of high energy X-rays in the treatment of cancer. It works by damaging tumor cells so they no longer multiply. Normal cells are also affected, as they are in chemotherapy, but the normal cells are not as sensitive to radiation as the cancerous cells.

Radiation does not cause pain (with only some exceptions) although the skin may appear burned. Side effects depend on the area of the body being treated and vary, with most patients experiencing no serious difficulty. Common side effects are loss of appetite, nausea, vomiting,

and diarrhea, fatigue and dry mouth and sore throat, and perhaps loss of taste, along with temporary skin irritation and loss of hair.

Hyperthermia is a relatively new procedure in the treatment of cancer. There seems to be a therapeutic response to heating the body to supernormal temperatures. The side effects of such treatment are normally irritation of the skin and, in some instances (as in radiation), burning of the skin.

Side effects experienced by the terminally ill patient may prevent him from being involved in an art therapy activity by lowering either his physical ability or emotional willingness, but, if involved, the process of art therapy may indeed allow the patient to better cope during his treatments, regardless of the side effects being experienced. If a patient is feeling better about himself, or is feeling emotional release following an art therapy session, that patient is better able to handle the physical and emotional stresses of necessary treatments. Imagery and visualization alone or combined with art* may also allow for pain reduction or control during treatments.

*More on imagery, visualization and the use of art to follow.

Thanatology Today (1980) noted that there are "three major therapies for the treatment of cancer: surgery, chemotherapy and radiotherapy (radiation). But there is a fourth therapy which is just as important: tender loving care."

THE USE OF IMAGERY AND VISUALIZATION IN ART THERAPY WITH THE TERMINALLY ILL

Susan Bach, a Jungian psychoanalyst, studies art of children, art that reveals both the psyche (mind) and the soma (body) of the child. Ms. Bach's studies have shown her that the individual artist/patient may unconsciously know precise medical information regarding his or her own disease, including malignant processes, exact localizations and prognoses. If art therapists are currently using art therapy for this purpose* the implications of such use are staggering to consider, cannot be dismissed and should be utilized to the highest potential.

Bach is not a stranger to Kubler-Ross. Of her work, Kubler-Ross (1978) has noted:

> "It is a method that reveals the inner meaning of spontaneous drawings where there is a free choice of form, color and design. These children very often reveal their knowledge of their own impending death and are able to share with those who understand the symbolic language the emerging of their illnesses, their life and their future."

Evidently, somewhere in our unconscious psyche, we are able to know the conditions and complications of our own soma (body). That knowledge comes through our drawings and art. The key is to see thatknowledge gained through our art to better know our inner beings and accordingly

*Aside from Bach, Kurtz (1979, ed. A.A.T.A.) is one therapist using art therapy in this manner. It is possible that in the future, art therapy may be used in conjunction with medical treatment, once more physicians begin to realize and accept the mind/body connection.

better our own lives and our patients' lives.

Jaffe (1980) explains that as the patient produces images in his mind to facilitate the healing process, he must take the time to examine them very closely. The picture created represents his illness and its healing communicates a great deal about what he knows or anticipates about his sickness. Also it is a representation of his inner hopes, fears, expectations and assumptions about himself.

The Jaffe (1980) process often follows this format: Patients are given, after relaxation and visualization, paper and colored pens (or other media) and asked to draw the healing image they have created in their mind. Then the picture is discussed. The images are always revealing, brimming with vividness and emotional truth.

> "The picture is not interpreted and then left alone. After some discussion, I ask the patient to look at it regularly during the week. A particularly good time to examine the picture and reflect on its meaning is just before and after a relaxation or meditation period. The power of the symbol may stimulate other images and information relative to the illness and the patient's life. Such drawings continually help people discover new aspects of themselves."

With the aid of relaxation techniques, the therapist is able to assist the patient to imagine, or visualize in his mind a particular situation, an emotion, a solution to a problem, or a particular process going on in his body, such as his terminal illness. Since the possibilities generated from visualization are endless, it is a very useful tool for the art therapist.

Visualization with the terminally ill may be used oftentimes for either reduction or control of pain.* This technique is based on the premise that our mental images may be able to directly affect our body (psyche affecting soma).

Jaffe (1980) notes that "as a mode of treatment, imagery has definite advantages. It has no negative side effects that may endanger or injure the ill person, nor can it conflict with or jeopardize other therapies." Other therapies, of course, are continued.** Imagery can be and is used with chemotherapy and radiation. "Therefore, an increasing number of physicians and health teams are experimenting with these exercises, adding them to the treatment process."

*Although Simonton (1978) is, at this time, using visualization as an actual component in the treatment of cancer.

**See Simonton's approach to cancer management in the next chapter.

For any art therapists planning to work with visualization with the terminally ill, Simonton (1978) and Jaffe (1980) should be reviewed, as both expertly explore the healing powers of imagery and visualization.

FUTURE IMPLICATIONS FOR THE USE OF ART THERAPY WITH THE TERMINALLY ILL

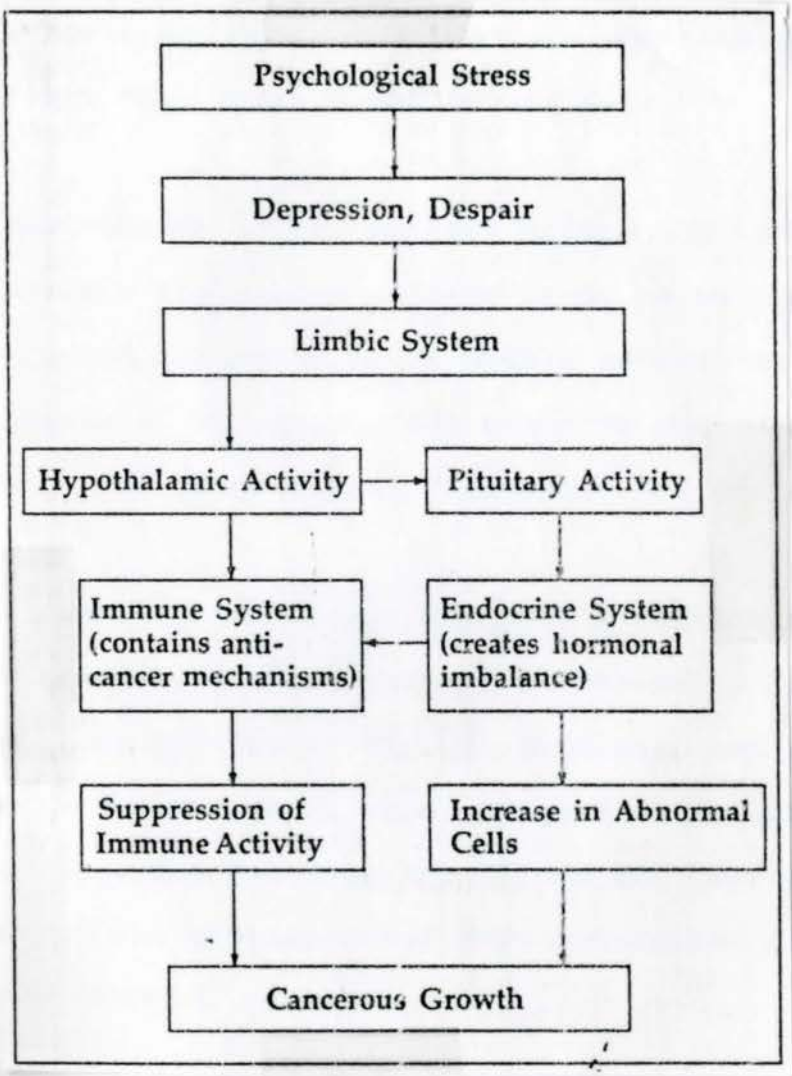
The implications of the future use of art therapy with terminal patients are chiefly:

1) Use of art therapy with both art and imagery in the manner of Simonton, etc.
2) Diagnosis of terminal disease through art (prior to the time the disease is diagnosed) in order to improve treatment and prognosis of the patient.

The fact that emotional factors may play a part in the development of cancer* has been explored and is becoming more accepted. Researchers have begun placing more emphasis on the somatic factors, on the link between emptional disturbances and physiological reactions. This link has to do with chemical changes in the hormonal environment or enzyme production brought about by emotional stress and has been entitled the "psychogenic theory."

Following is Simonton's (1978) Mind/Body Model of Cancer Development:

*Although emotional factors in the development of a number of diseases have been explored, said research in the development of cancer is most widely known.



What this model signifies for the art therapist, and, indeed, for all those in the mental health professions, is that psychological stress, despression and despair play a significant part in the development of disease.*

*This premise has yet to be proved, but there is much research and literature to this effect, Simonton (1978) being one of the most widely known.

Drawings and other forms of art are often used to analyze inner emotional conflict with the assumption being that drawings and art allow more spontaneity (i.e., truth) than other forms of analysis.

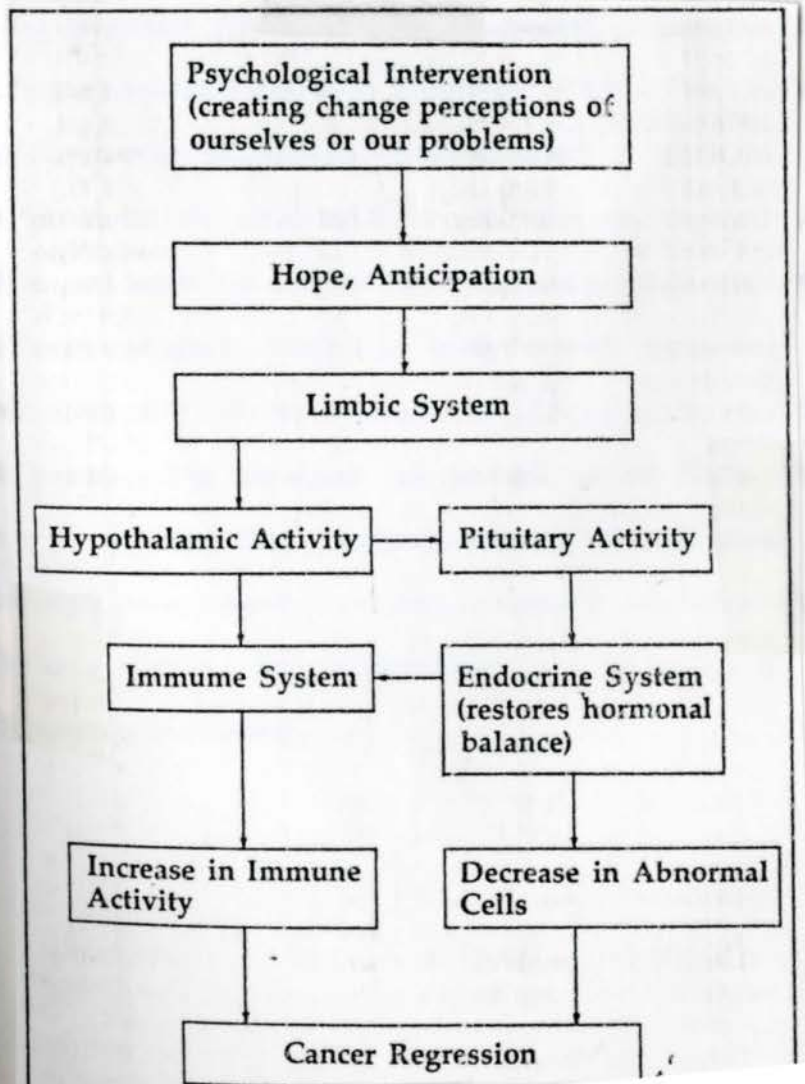
Bahnson and Bahnson (1963, editors Kissen and LeShan) have noted that the cancer patient tends to be rigid and constricted and seems to be unable to utilize his inner potentials. He seems withdrawn from emotional involvements and makes use of repressive and denial defenses.

Emotional rigidity and withdrawal pose a problem for the art therapist. A rigid, withdrawn person is likely to be unwilling to want to express emotions, let alone work in an art media, work which not only immediately expresses repressed feelings but allows for continued expression of the emotion until that particular piece of art is destroyed.

If, in fact, cancer development, or the development of any terminal disease, is the result of psychological stress, depression and despair, then psychological intervention becomes a very important and required intervention process against terminal disease. Whether that intervention is psychiatric (by an M.D.), by a psychologist, or by an art therapist, intervention

represents a very real need. If the cancer patient is, indeed, unable to express hostility or does have a tendency to hold resentment in, then art therapy would seem a viable form of psychotherapy, if not preferable.

Following is Simonton's (1978) Mind/Body Model of Cancer Development. What is presented here is that psychological intervention is necessary in order to begin the changes in the body's systems to increase immune activity and decrease abnormal cell production-for the regression of cancer.



As noted, visualization is used in conjunction with other modes of cancer treatment. Simonton's (1978) psychological approach in cancer management is as follows:

1. Continue all medical treatment.
2. Allow the patient to see the role the patient and his way of living has played in the development of the disease.
3. Discuss secondary gains, such as gains from being ill (attention, etc.).
4. Educational orientation sessions (importance of attitudes, belief systems, "will to live").
5. Group and individual treatment.
6. A process of relaxation and visual imagery. The patient is asked to visualize his cancer, his treatment, and his body's own immune mechanisms (white blood cells) acting on the disease; the patient is asked to do this three times daily. The imagery askes the patient to accept treatment currently being administered (e.g., radiation, chemotherapy) as well as to change attitudes.

If, in fact, some development of cancer might conceivably result from the physiological effects of continued inner stress which has remained unresolved by either onward action or unsuccessful adaptation, then therapy is of tantamount importance in the treatment of cancer and other terminal disease.

PERSONAL MANAGEMENT OF THE THERAPIST WORKING WITH THE TERMINALLY ILL

How involved does the therapist become with the patient? Kubler-Ross (1974) states that "there is no way to remain the slightest bit aloof from a dying friend or patient if you want to keep the channels of communication open and share the experience." It can also be said that a therapist needs to become deeply involved with the patient and then be able to "switch gears," be able to leave the patient and go on with her life apart from the patient and apart from the death counseling role.

It is not uncommon for any person working with the terminally ill to be questioned as to how they are able to deal with and work on a daily basis with terminally ill patients; how they are able to handle their own emotions in the face of the suffering and death they see; how they can manage not to be personally affected by these experiences.

Most of the agencies and hospitals working with terminally ill patients require regular attendance of all staff at "support meetings," meetings which give participating members the opportunity to share their emotions, both negative and positive, ventilate frustrations, fears, and sadnesses, along with shared

communication of learned knowledge regarding particular patients and care of the terminally ill in general.

Without such support groups, those working with the terminally ill are likely to suffer "burn-out," a condition which involves the inability of a professional person to experience positive, caring feelings towards the patients he works with. Burn-out is a form of emotional exhaustion. Thanatology Today (1980) says, "Burn-out and stress among professional caregivers to people with life-threatening illnesses, the dying and their survivors are epidemic."

Maslach (1979, ed. Garfield) outlines a program to prevent burn-out in those working with the terminal or chronically ill patient. He stresses training in interpersonal skills, analysis of personal feelings, social-professional support systems, use of humor, amount and variety of patient contact, separation between work and home, and upkeep of physical health.

Bugen(1979, ed. Garfield) went on to chart the management of the emotional responses of caregivers, listing both internal and external resources important in such management.

Klagsbrun (1979, ed. Garfield) has also expressed the importance of sharing, sharing indicative of support groups or meetings. He has noted that

> "we all realized that our ability to talk about death and cancer with the patients and to bear their needs without closing ourselves off from them grew in direct proportion to our ability to share our own anxieties at our group meetings. The more we talked together, the more easily we could listen to our patients."

Bugen (1979, ed. Garfield) has noted that without being conscious of it, "persons in a helping role are vulnerable to a wide variety of unpleasant, negative manifestations of anxiety. These aversive states include anger, guilt, helplessness, frustration, and feelings of inadequacy."

In many ways, those working with the terminally ill suffer the same feelings of helplessness, frustration and sorrow as those family members who suffer the loss of a loved one. Perhaps the experiencing of these emotions is the factor that allows the individual working with family members to relate, to counsel, to support and assist. The therapist working with the terminally ill experiences both the patient's despair of coping with the terminal illness and the family members' loss of the loved one. And although most therapists working with the terminally ill have the assistance of a support group, each patient's death is experienced as a loss.

The experiencing of these emotions and the experience of loss are issues that must be continually dealt with in order to prevent burn-out in professionals working with the terminally ill and their families. It is also, however, the experiencing of these emotions and the experience of loss which allow professionals to understand what process the patient and the patient's family are going through and, accordingly, better assist the terminally ill.

SUMMARY AND CONCLUSIONS

Kubler-Ross (1975) has noted that "dying can be a nightmare in a depressing, sad hospital, but it can also be a time of growth, creativity and peace. The art therapist may be the catalyst for such growth in the patient." Indeed, Kubler-Ross noted that a therapist's "role in their struggle is as a catalyst, to share a moment, a tear perhaps, a hope, and most of all, to lend a listening ear."

Levitt and Guralnick (1979) in describing human contact as "the most potent medicine of all, " listed suggestions for the therapist (or visitor) visiting the terminally ill. These bear repeating to the caring therapist.

When visiting the dying patient, therapists might remember the following:

1. Visit often and do not, at some point, abandon the patient.
2. Inform the patient ahead of time if a visit has to be canceled.
3. Talk to the patient about subjects that interest him.*
4. Engage the patient in any social or creative activities that he is capable of performing.

*See Appendix for guidelines for "Active Listening."

For an art therapist, an art activity is appropriate. However, activities such as a walk, a card game, a movie, a book discussion, etc., may also be appropriate.

5. Be understanding and try to sense what the patient is undergoing.
6. Touch the patient to let him "feel" the presence of someone next to him; for example, put an arm around his shoulders, hold his hand.
7. Sit on a chair next to the bed or sit on the bed, to show closeness and affection.
8. Let the patient know that he will not die alone. Assure him that someone will be there to say goodbye and bear witness to his passing.

Following is a brief summarization of art therapy with the terminally ill. The use of art therapy with the dying has been established and art therapists are already an important component in the care and counseling of the terminally ill.

Purpose of Art Therapy with the Terminally Ill

1. To assist the patient in achieving self-acceptance and acceptance of the death process.

2. To assist the patient in expressing his emotions of anger, denial, depression, etc., often experienced during the terminal illness.
3. To allow for pain reduction and control through the use of art combined with imagery and visualization.

Enviroments in which Art Therapist Work with the Terminally Ill

1. Outpatient clinics.
2. Hospital oncology units.
3. Hospice (inpatient) settings.
4. In the patient's home.

Adaptable Art Forms for Art Therapy with the Terminally Ill

1. Sketching or drawing.
2. Painting.
3. Collage-making.
4. Use of clay.

Problems Often Experienced in Work with the Terminally Ill

1. Mutual pretense used by most terminal patients.
2. Physical limitations and incapacities experienced by the patient.
3. High percentage of stress and burn-out experienced by those working with the terminally ill.

4. Lack of spontaneity found in the terminally ill patient, similar to that lack of spontaneity found in the geriatric patient.
5. Lack of funding and/or salaried jobs for art therapists who wish to work with terminally ill patients.

Rewards for Those Working with the Terminally Ill

1. Better understanding of the death and dying process.
2. Better understanding and appreciation of life (with the realization that life is limited and that now is the time to live).

Areas for Further Work and Research by Art Therapists

1. How the use of supportive therapies such as art therapy influences the patient's ability to cope with illness and impending death.
2. How art when used with imagery and visualization can reduce or control pain in cancer patients.
3. The mind's influence on the course and outcome of therapy (and possibly on the development or remission of cancer).
4. The relation of mortality and creativity.
5. Use of art therapy in grief and bereavement counseling and the effect of art therapy on anxiety, depression, and physical illness and/or death of the surviving family members.

his paper has focused on the process of art therapy with the terminally ill. Basic theory behind this therapy may be used by counselors, psychiatrists, chaplains, etc. Art therapists do have an advantage over other forms of therapist, in that through art patients are oftentimes more able to express their emotions, anger, rage, and sadness; are more able to express how difficult it is to live, and how difficult it is to die.

Kubler-Ross (1975) writes

> "it will always be hard to die, but if we can learn to reintroduce death into our lives so that it comes not as a dreaded stranger but as an expected companion to our life, then we can learn to live our lives with meaning- with full appreciation of our finiteness."

A therapist working with the terminally ill needs to understand the value of human life, the fear of dying; be able to sympathize, and be able to look for ways of making the last days more tolerable. And that is what therapy with the terminally ill is all about.

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COMMENT

The hardest state to be in is one in which you keep your heart open to the suffering that exists around you, and simultaneously keep your discriminative wisdom. It's far easier to do one or the other; keep your heart open and get lost into pity, empathetic suffering, righteous indignation, etc.; or remain remotely detached as a witness to it all. Once you understand that true compassion is the blending of the open heart and the quiet mind, it is still difficult to find the balance. Most often we start out doing these things sequentially. We open our hearts and get lost into the melodrama, then we meditate and regain our quiet center by pulling back in from so much openness. Then we once again open and get sucked back into the dance. So it goes cycle after cycle.

It takes a good while to get the balance. For at first the discriminative awareness part of the cycle makes you feel rather like a cold fish. You feel as if you have lost your tenderness and caring. And yet each time you open again to the tender emotions, you get lost into the drama and see your predicament; if you really want to help others who are suffering, you just have to develop the balance between heart and mind such that you remain soft and flowing yet simultaneously clear and spacious. You have to stay right on the edge of that balance. It seems impossible, but you do it. At first when you achieve this balance it is self-consciously maintained. Ultimately, however, you merely become the statement of the amalgram of the open heart and quiet mind. Then there is no more struggle; it's just the way you are.

Ram Dass

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APPENDIX

THE PATIENT'S BILL OF RIGHTS

WHEREAS, The American Hospital Association has recently approved a Patient's Bill of Rights with the expectation that observance of the rights will contribute to more effective patient care and greater satsifaction for the patient, the patient's physician, and the hospital; and

WHEREAS, The American Hospital Association in developing these rights, has done so in the expectation that they will be supported by physicians and hospitals throughout the nation on behalf of their patients as an integral part of the healing process; and

WHEREAS, The California Hospital Association Board of Trustees has recently endorsed the Patient's Bill of Rights in hopes that such rights will be observed by all hospitals operating within the State of California; and

WHEREAS, Patients, physicians and hospitals throughout the State of California deserve to have these rights recognized and supported by the hospitals and physicians within this state; now, therefore, be it

RESOLVED, That these rights are as follows:

1. The patient has the right to considerate and respectful care.

2. The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in his behalf. He has the right to know by name the physician responsible for coordinating his care.

3. The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include but not necessarily be limited to the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation. Where medically significant alternatives for care or treatment exist, or when the patient requests information concerning medical alternatives, the patient has the right to such information.

   The patient also has the right to know the name of the person responsible for the procedures and/or treatment.

4. The patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his action.

5. The patient has the right to every consideration of his privacy concerning his own medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly. Those not directly involved in his care must have the permission of the patient to be present.

6. The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

7. The patient has the right to expect that within its capacity a hospital must make reasonable response to the request of a patient for services. The hospital must provide evaluation, service and/or referral as indicated by the urgency of the case. When medically permissible a patient may be transferred to another facility only after he has received complete information and explanation concerning the needs for and alternatives to such a transfer. The institution to which the patient is to be transferred must first have accepted the patient for transfer.

8. The patient has the right to obtain information as to any relationship of his hospital to other health care and educational institutions insofar as his care is concerned. The patient has the right to obtain information as to the existence of any professional relationships among individuals, by name, who are treating him.

9. The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to participate in such research projects.

10. The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and where. The patient has the right to expect that the hospital will provide a mechanism whereby he is informed by his physician or a delegate of the physician of the patient's continuing health care requirements following discharge.

11. The patient has the right to examine and receive an explanation of his bill regardless of source of payment.

12. The patient has the right to know what hospital rules and regulations apply to his conduct as a patient; and be it further

RESOLVED, That the hospitals currently licensed and operating in the State of California are hereby requested to post a suitable copy of the Patient's Bill of Rights or of this resolution in appropriate places within each hospital so that such rights may be read by patients being admitted into such institutions; and be it further

RESOLVED, That all physicians, dentiests, podiatrists and other health professionals providing care and treatment for patients in hospitals within the State of California are requested to observe the rights of the patient as set forth above, and to actively assist hospitals and all those engaged in the performance of health care services within the State of California in the observance of these rights; and be it furtehr

RESOLVED, That the Chief Clerk of the Assembly transmit copies of this resolution to the Directors of the California Hospital Association, California Medical Association, California Dental Association and Califronia Podiatric Association.

HOUSE RESOLUTION No. 69 As Amended by Assemblyman Lanterman
Adopted by the Assembly August 10, 1973

QUALITIES LOOKED FOR IN PATIENT CARE ASSOCIATES

Compassion

High tolerance of ambiguity

Ease in talking about dying (as evidenced by discussion that is personalized as opposed to merely philosophical)

The ability for introspection

Healthy sense of self-confidence

A high tolerance for frustration

A sense of humility that allows one to view sharing in someone else's dying as a joint process with learning occuring on both sides

The ability to speak and understand various metaphors (religious, cultural or symbolic)

Relevant professional training in counseling, psychology, social welfare, nursing or medicine

Brotman Medical Center
Thanatology Program, 1980

ACTIVE LISTENING

1. Human needs--attention, acceptance, approval, affection

   a. consider the individuality of each person as he/she experiences and tries to deal with these needs.

   b. all human behavior is purposeful and thus understandable.

2. Thoughts and feelings are communicated verbally and non-verbally. Learn to:

   a. listen and see what is behind the words.

   b. be present to the person; show you are <u>trying</u> to understand how he feels.

3. Reassure and support with a non-threatening, non-judmental attitude.

   a. accept the person's right to say, do and be--whatever he says, does, and is.

   b. work through your personal feelings with your supervisor and Volunteer Support Group.

4. Techniques:

   a. show external signs of listening by eye contact, nodding appropriately, smiling, gestures, posture.

   b. if you are unclear about something your patient says, ask a clarifying question such as, "What do you mean?"

   c. be careful that your specific questions are to clarify what the other person wants to communicate, not what you hope he is leading up to.

   d. allow time for silence and thought; calm silence builds trust; try to feel comfortable with silence. Silence is O.K.

   e. observe signals that a person wants to talk--leaning forward, seeking eye contact with you, stealing glances at you, etc. Invite the person to talk.

   f. do listen within the framework of the other person's purpose; seemingly light social conversation may be leading to a concern--it may also be a need for light social conversation.

   g. listen just as intently to the person's nationality, color, religion, experience, conditioning and feelings as you do to words.

h. use words the speaker himself uses as much as possible, but be natural.

i. particularly when the person is able to speak only in incomplete ideas, repeat back to him the gist of what he says briefly so he can realize how far he's progressed with the idea and can continue further <u>if</u> he wants to.

j. if words expressing feelings are used, form a question such as "You said that made you feel 'alone;' what do you mean?"; it is his right to expand or not.

k. self disclosure can be helpful to a patient when used sensitively and compassionately with the patient's needs in mind, not your own.

5. Non-verbal communication:

a. communication is facts and feelings--words frequently express neither.

i. learn to listen and see behind the words; examples:

a) the composure of the person

b) external environment

ii. instead of saying "you're sad,"say "you're crying;" allow the person the opportunity to express the feeling behind the action, if he wishes.

iii. <u>after a trusting relationship has developed</u>, when you hear "I'm O.K.," you may say "your hands are fidgeting;" he may respond or not. (Confrontation is a technique which should be used sparingly, if at all.)

From New Haven, Connecticut
Hospice Volunteer Program
September, 1974--September, 1975