Death, Dying and Grief: The Last Psychic Barrier

Eileen Tarnoff

*Counselor, Response Center, Chicago, Illinois**

The answer was to develop an educational approach to death and dying, an approach that would de-mystify the issues, one where the taboos, as well as the rituals and practices could be discussed openly. This would then help the adolescent gain control early, often prior to a death experience, thereby allowing the adolescent some control over his environment which he would need when coping with the dying and mourning process.

Today, the subject of death and dying has become a popular one, but why? What reasons are there now for focusing on the process of dying and the mourning reaction that follows? Death is not a new process; people have always died, they will continue to die. Therefore, what is so important to understand? It's a simple fact of life—a universal given!

What is important to understand is how people react to this given. Yes, people will always die. But the death process and the client's psychological adjustment to that process as well as the family's coping mechanisms are what's important to understand.

Often families are unable to cope with a fatal illness of a family member and turn to therapy as a means of helping them gain a new homeostasis.

An illustration:

> Amy, age 20, recently called requesting counseling. She stated, "I want counseling for myself and my brothers and sisters. My sister, who is 18, has terminal cancer and the whole family is falling apart. I can't cope with what is happening to Jamie and the effect her illness is having on me. My brothers and sisters feel the same way. Can you help us?"

"Mourn" and "die" are both active verbs indicating "doing" processes. It is our professional responsibility to help bring them to a psychological level most healthy for the client and the client's family.

> Susan, Amy's sister, recently stated, "I am now able to see Jamie and my relationship in a new light. We are growing closer every day. I think now, that when she dies, I will feel like I've done everything to help both her and myself."

The Response Center, the home for The Project on Adolescent Mourning Experience is an adolescent counseling center. Clients with a wide range of problems are seen, including family, peer, sexual, identity, and life crises to name a few. A year and a half ago, Joan Ravenna, the project's originator, began noticing a significant number of clients who were dealing with grief over the recent or not so recent death of persons significant to them.

In June of 1977, The Response Center received a one-year grant from the Chicago Women's Aid for the exploration of this issue. Thus, the Project on Adolescent Mourning Experience was born. The initial grant was augmented nine months later with a gift from a local funeral home.

These grants have allowed the Response Center to test and further explore our hypotheses concerning the uniqueness of the adolescent mourning experience. Our hypothesis rests on the notion that an adolescent, during his normal development, will mourn numerous losses. These include loss of control over his body during the transition from childhood to physical maturity, and changes in peer relationships from the pre-adolescent horde to the adolescent clique and, the most

* Response Center, a project of the Jewish Federation of Metropolitan Chicago, is a multi-disciplinary social service and medical center for adolescents. Funding for the first year of the Project on Adolescent Mourning Experience was provided through the Chicago Women's Aid in honor of their ninety-fifth year of service.

difficult, the loss of childhood relationships with parents. Consequently, it becomes difficult to separate developmental mourning issues from those associated with death. The concern is how the loss of a primary person affects the adolescent's emerging identity.

In structuring the Project on Adolescent Mourning Experience, consideration was given to staff development. It became apparent as the project progressed that the issues of death and dying evoked strong feelings in everyone. Professionals have a responsibility to both themselves and their clients to be aware of their own vulnerabilities as evoked by their clients' turmoil as the clients struggle to gain control over their losses.

Staff needed a place to come together to share treatment issues and related feelings. A "debriefing" group was set up for which an outside facilitator was hired. The purpose of this group was to enable staff to sort out client-related issues from personal issues.

In addition to this group, there were treatment and religious issues on which focus was needed. A staff consultant*, was hired who, in addition to teaching courses on Death and Dying at a local college, had for several years worked closely with Dr. Elizabeth Kubler-Ross. She helped staff focus on treatment issues which ranged from grief stages to contract-setting issues. Religious leaders also were brought in to provide staff with a knowledge-base related to rituals and practices regarding death and dying.

One could not study issues of death and dying without including the funeral industry and its importance. What followed became a unique experience for all staff. A meeting was arranged for staff to meet with a funeral director at the funeral home. Time first was spent in the chapel where the funeral director discussed funeral prices, funeral procedures and options; laws regarding death issues and family responsibilities. From the discussion in the chapel, staff went into the casket room and finally into the embalming room. Feelings of helplessness and loss of control were the universal staff reaction. If this was our feeling as non-grievers, how intense were these same feelings then for people who were grieving? Staff felt this experience was to be of utmost importance as we later worked with grieving clients. Through this experience we could help our clients gain control over the unknown of the funeral process and its implications for them.

As the main purpose of the project was to provide mental health services to the adolescent population, we needed to explore how this could be done most effectively.

First, we looked at the Center's existing services, which include group, individual and family treatment. These were evaluated as valuable services for any psychological issues. However, due to the unique process of the adolescent mourning experience, the question remained, what else could be offered to this population? An additional potential mode of treatment could be that of family groups where several families would come together to share and explore their feelings. In such groups the surviving parent as well as the adolescent could share feelings and ideas and learn how other families are coping with the issues of mourning. Group treatment could be of particular importance to adolescents, as adolescence is characterized as being a period where one's peer group is of utmost importance. What better way to validate one's feelings than with peers sharing the same experience of loss.

Therapy is appropriate for the adolescents and/or their families who are requesting services, after identifying loss of an issue. But what about the rest of the population, those individuals who are grieving but are unaware of the effects of the grief process on them? How were they to be served?

The answer was to develop an educational approach to death and dying, an approach that would de-mystify the issues, one where the taboos, as well as the rituals and practices could be discussed openly. This would then help the adolescent gain control early, often prior to a death experience, thereby allowing

* Audrey Gordon.

the adolescent some control over his environment which he would need when coping with the dying and mourning process.

> Steve, age 21, was involved in counseling as were his siblings regarding their sister's impending death. During one of the family sessions, Steve reflected back to high school. He spoke about a course he had, related to the issues of death and dying. He stated he never thought much about the course since high school, but now, with what he learned then, he could better understand what Jamie was going through and what his own reactions were all about.

In order to communicate the project's goals to the community, staff began to contact professionals in the immediate area and surrounding suburbs. Contact was initiated with clergy, schools, both public and private, other social service agencies, hospitals and funeral directors, first by letter, then by telephone calls. The nature of the letter sent was not to seek referrals but rather to speak to other professionals regarding the project opening the line of communication regarding an important issue. The overwhelming reaction to our contacts was one of massive denial:

1. Hospital social workers said they only deal with the dying—survivors' grief therefore isn't their concern. Doctors, "not we," deal with the families, and they provide whatever is needed.
2. School social workers felt that, yes, grieving was an issue, but that it's up to the family to handle the problem. It's a family concern, not a school issue.

The most perplexing responses were from the clergy:

1. Religious leader A stated that grieving adolescents were not a problem in his congregation.
2. Religious leader B felt that religion was the answer for mourners and that grieving wasn't a long-term process. He went on to say that after 3-6 months he felt grief issues were usually resolved.
3. Religious leader C stated he may have as many as two funerals a week, but really had little contact with the family following the funeral or *shiva* period.
4. Religious leader D felt adolescent grief was a unique issue, but he rarely came into contact with the adolescent population. He felt the adolescent was too angry with God to speak openly with a representative of God.

The group that was most responsive, as expected, was the facilitators of the various widow-to-widow groups in the area. Through their membership they saw the importance of successful "grief work" and the consequences of the failure to complete the grief process. These people served as an inspiration to continue to pursue this program regardless of the other reactions previously described. They reinforced the importance of helping the adolescent cope with an important and inevitable part of life and a part of life no one wants to talk about.

High School Course

Based on our contacts and their reactions, it was determined that the project's success rested not only on treatment but on community education as well. Our greatest success in establishing contact occurred through one of the local high schools with a one-week mini-course on Death and Dying. We used our existing and most positive relationship with the school and its administrators to help create a new and innovative program with an existing curriculum. The issues of death and dying were finally given an arena, an arena to explore the adolescents' knowledge, fears and misinformation regarding an issue which faces us all: death, dying and grieving.

In order to present this workshop the staff needed not only administrative approval but a willing teacher and her classroom. This was accomplished through the social studies department and in particular a senior psychology class.

This class was selected because, according to the school's curriculum, it was an elective course. Specifically this meant that the students involved were *interested* in psychological issues and therefore would be more

receptive to what was to be offered. As this course was not required and because this workshop was a departure from the standard curriculum, it was offered as an option for the class. Anyone, for any reason, could decide not to sit in for the week. It is important to note that out of a class of 32 *no one* opted out. Equally important, for one full week in the class, no one cut.

The course was given in the form of lectures. However, the emphasis was also on class participation, both experimental and through structured problems. This was not intended to be a therapy experience.

The goals of the course were to:

a. Inform students about death.

b. Clarify the grief process and make students aware of emotions concerning the death of significant others.

c. Help participants to become informed consumers of medical and funeral services.

d. Pose socio-ethical issues and begin processes of value clarification.

e. Allow those participants who had grief issues or wanted more information an opportunity to identify the Response Center as a resource.

The course covered a wide range of issues from the concept of euthanasia to funeral procedures. At the beginning of the seminar participants were given a booklet. It included a questionnaire; the purpose was to allow the individual a chance to focus privately his/her thoughts concerning death and its related issues. The questionnaire included such questions as:

1. Can you imagine your own death? Describe.

2. Are you interested in any dangerous sports, e.g. racing, mountain climbing, etc.

3. Have you discussed death . . . a. With your family? b. With others? Describe the main views of death given.

4. Do you believe in immortality, and/or an immortal soul? Discuss and specify kind.

5. Do you think that you can be punished for your sins after death?

6. What kind of death and funeral would you prefer?

8. Should a dying person be kept alive under all conditions? Under what conditions, if any, should one not be kept alive?

The questionnaire did not have to be turned in; however, it was suggested that the questions be reviewed both at the beginning and again at the end of the workshop in order to see if any views had changed.

Besides the questionnaire, everyone was given a copy of *The Living Will,* prepared by the Euthanasia Educational Council. *The Living Will* is a document through which an individual can determine his own finality should "a situation arise in which there is no reasonable expectation for recovery." The document goes on to state that "I be allowed to die and not be kept alive by artificial or heroic measures. I do not fear death itself as much as the indignities of deterioration, dependence and hopeless pain. I therefore ask that medication be mercifully administered to me to alleviate suffering even though this may hasten the moment of death."

Not surprisingly, this led the class into a prolonged and provocative discussion of euthanasia, both active and passive, as well as the legal, moral, and philosophical definitions of death. The class unanimously was in favor of passive euthanasia. However, the reaction to active euthanasia was mixed because students could not agree what was defined by the term active.

Death, we felt, could not be discussed without including the family and its involvement. We therefore constructed one of our exercises to illustrate this point. The Sanders Family was then created consisting of mother, father and two siblings, age 16 and 20. The situation went as follows:

> Dr. Fitzgerald has told Mrs. Sanders that her husband has terminal cancer, with a prognosis of six months. Mrs. Sanders, overwhelmed with this information and needing family support, had decided to tell her children the prognosis.
>
> Mr. Sanders is aware of the serious nature of his illness, but has not been told the

prognosis. Dr. Fitzgerald has left the decision of what to tell Mr. Sanders up to his family.

The class was then divided up into groups of three with the task being to decide:

1. Should Mrs. Sanders share this information with her family, if so how?
2. What does the prognosis mean to the Sanders' family?
3. Should the family tell Mr. Sanders the prognosis?

The results were most interesting. Three out of the six "families" decided to tell Mr. Sanders. Two of the other "families" decided against telling Mr. Sanders. Of those two the children of one were not in accord with their mother's decision. The last family changed its focus, whereby Mrs. Sanders decided to share the information first with her husband and then to have both parents talk with their children.

The issues that this problem raised were:

1. Family systems and communication patterns.
2. Male role sterotypes.
3. Value systems.
4. Coping mechanisms.

Through this and similar exercises, the students were able to focus on issues that could be important to them personally, without feeling they were revealing themselves to other class members. This allowed them some insight as to how they possibly might handle these issues when they arise in the future.

The response to the course was extremely positive. Students found the information very enlightening. They stated the subject matter was one that their families were reluctant to discuss with them yet one in which they wanted more information.

Because the course was basically didactic and the time was limited, we offered a follow-up workshop at the Response Center. Of a class of 32, eight were interested in the follow-up workshop. It's important to note that everyone attending the workshop had grieving issues.

The fact that all were grievers wasn't at all surprising. To take it a step further, this data confirmed our hypothesis regarding the importance for adolescents to gain control over grieving issues both conscious and preconscious.

This teaching experience further demonstrated to us the heavy emotional investment attached to the issues of death and dying. It further demonstrated the universal taboo, that death and the dying process are not to be discussed because it may cause pain. We are now more convinced in our belief that through supportive educational experiences, adolescents can come to understand the grieving process and know when it is incomplete or when it has been halted, thus enabling them to seek therapy when necessary.

The project on Adolescent Mourning Experience has now completed its first year. Through this program, we have learned an enormous amount regarding adolescent grieving and the need for death education.

Ten-Stage Grieving Process

The grieving experience has unique features for everyone who is coping with a loss. Although the individual experience is unique, the general stages a person goes through are generalizable. Dr. Elizabeth Kubler-Ross has identified a five-stage process for the dying patient and she states the family goes through a parallel process. An article in *Today's Health* expands on Dr. Kubler-Ross's stages and breaks down the grief process further—into ten stages, which in modified form we believe more accurately depicts the adolescence's grief process.

The first stage of grief is one of shock and denial. A typical question that first arises is: How can this be happening to me? This isn't really true. Adolescents attempt to cope by neutralizing the situation and stating that the loss doesn't really affect their lives. They are typically self-centered. Therefore, they remain caught up in their own world as a means of denying what is happening to them.

John, age 14, after consoling his mother following the news of his grandmother's death, said he had to go to gymnastics

practice. He left before his mother could respond. His mother was very perplexed by his behavior and took it that John just didn't care about his grandmother's death. She couldn't understand this as she always felt that John and his grandmother were very close.

The second stage is one of emotional release. This stage is usually accompanied by a feeling of sadness with a sense of vulnerability described as loneliness and fear of abandonment. At this time, the need for a support system is especially strong. However, as now the adolescent is struggling to break the ties of his family support system and gain independence, it is difficult for him to seek support from his family. His peer-group members are of little help as they are caught up in their own world and therefore are usually unable to be of support for any duration of time. Consequently, in order to regain a sense of equilibrium as quickly as possible, the adolescent will immerse himself in his own struggles or begin to act out so others will notice him and thereby help him regain control.

John, shortly following his grandmother's funeral, found himself feeling confused. His mother began looking to him for support and in turn he moved further away from her. He tried to talk to friends but after a while they all became disinterested; John then began staying away from home as much as possible in order to avoid confrontations with his mother. At the same time he began feeling isolated from his friends.

While the adolescent may continue to act out as means of gaining attention and subsequent control, he also acts out in order to ward off depression, the third stage of grief.

The fourth stage, as we see it, is one of panic. It is at this point that the adolescent can think of nothing else but the loss. Adolescents define this stage as one of fear of what others will say.

John, several months later, still cannot stop thinking of his grandmother. He spends so much time thinking about her that his grades have begun to slip. His friends are now moving away from him as they don't understand why he's acting so strange.

The stage of guilt is a difficult one for the adolescent. Since as an adolescent he is experiencing guilt concerning many areas of his life, a loss at this time becomes even more difficult to assimilate. Often the guilt then manifests itself in remarkable fluctuations of mood, intense dependency conflicts, and an insatiable need for affection.

John now began feeling guilty for all the trouble and anguish he had caused his grandmother. He began questioning whether she could ever have really loved him because of all he had done. In turn, he began questioning how anyone could love him. To test whether he was worthy of love he began testing every meaningful relationship he had.

The stage that follows is one of hostility and projection. The adolescent turns his rage toward the lost person. Now the loss is looked upon as a great inconvenience which has both disrupted his relationship with this person and also inconvenienced his lifestyle. This stage may lead to adolescent depression. Often guilt will emerge again as the adolescent struggles with the fear of having unacceptable impulses and feelings. At this time the adolescent needs help to understand that his rage is normal.

Through this stage, the mourning period is accepted by society as a natural process. Generally people are sympathetic toward the mourner for about three months following the loss. After three months, the expectation is for one to resume "normal" living. Consequently, the mourners may now stop talking about their feelings and instead suppress them. No matter how much the mourner tries to resume normal living, he is still unable to do so. The adolescent will indeed suppress his feelings only to have them flair up again, often through outbursts of self-destructive behavior or through withdrawal from his friends and family.

John no longer feeling he can talk to anyone about his grandmother, pretends both to himself and the world that everything is fine. He can't understand why he doesn't have any energy for his studies or his first

love, baseball. He gradually becomes frustrated with himself and begins acting out both at home and school.

The adolescent often becomes stuck at this stage of internalization and is unable, due to lack of maturity, to move forward. It is during this stage, which may be some time after the loss, that the adolescent may call attention to himself as a way of seeking help.

The final stage of the grief process is when the adolescent has re-adjusted to life. It is not being back to his old self because that will never happen, since the adolescent is different because of the grief experience. However, the adolescent will be able to resume life activities without being in constant pain from thoughts of the lost person. The completion of the grief process can take up to two years.

Treatment Considerations

In determining how to provide treatment for the adolescent, staff needed to re-evaluate the intake process because it became apparent to us that adolescents usually do not openly acknowledge themselves as grievers. The adolescent, we concluded, only identifies the role of griever on his terms, so he can remain in control and not feel "like a freak" as one of our clients described himself.

A new focus was then added to the existing intake structure, that of mourning experiences. Staff looked for mourning experiences as they focused on issues such as:

1. Unusual stress during the past year.
2. Abrupt changes in the family system.
3. A recent move.
4. Changes in physical health of any family member.

When a client then began relating experiences which could lead the worker to feel there were grief issues, another change in intake procedures took place. The intake worker continued beyond the intake process to become the primary worker as well, in order to avoid another loss experience for the client.

The grieving adolescent uses therapy in a number of ways and under a number of different circumstances. The most prevalent use of treatment is what staff has defined as the "Dump and Run Syndrome" as exemplified by Carey.

> Recently the Response Center sought adolescent volunteers for some roleplay experiences. Carey, age 14, volunteered. He was given the option of several role situations, one being that of a griever. He chose the griever stating that that would be easy for him as his mother died two years earlier. As the role play unfolded, it became obvious that he wasn't role playing at all, but actually was using this as a therapy experience for himself. Following the role play situation, no further contact was initiated by him and he refused any outreach attempts made by the staff.

Carey used this role play experience to work out some of his unresolved grieving issues but felt no need for more intense, ongoing involvement, thus the phrase "Dump and Run."

From the experience of Carey and others like him, staff began to reappraise the concept of treatment contracts. This pattern pointed out the need for an on-the-spot contract and treatment intervention, as there may not be a second chance to intervene.

The adolescent may seek help around an anniversary reaction, an acute state of depression or use any number of unrelated issues in order to enter treatment, even if only for one session. As this has appeared to be a trend, the role of a therapist therefore needs to be fluid and flexible. Often a grieving adolescent is looking for someone to validate his feelings and to reassure him that he will survive what he is experiencing. At other times the therapist becomes a role model or surrogate parent. Treatment, especially in light of the tendency for a griever to dump and run, is an intense experience for both client and therapist, even in one session. For the grieving adolescent who chooses to remain in treatment, another pattern has developed.

> Jessica, age 15, sought treatment as she felt she was overly concerned about her aunt's illness. No one in the family was sharing any information with her and so she began to

"spy" in order to find out information. She felt guilty for spying. She wondered if she was crazy for being so concerned since everyone was saying her aunt would be fine.

Jessica's intuition was correct. Between her second and third session, her aunt died. The family, still feeling the need to protect Jessica, did not allow her to attend the funeral.

Jessica spent several sessions focused on the loss of her aunt and the anger at her family for protecting her. Suddenly there was a shift in issues. Jessica now was focusing on her impending school debate and her need to practice more. Just as suddenly again, she would shift back to grief issues.

Jessica, although concerned with mourning issues, also had a need to sort out developmental concerns. She would, through her constant shift of tasks, have control over how she wanted to use therapy. Grieving issues were presented only when she felt safe and secure in doing so. This tendency to intersperse grief tasks and developmental issues is often difficult for the therapist to follow, yet it is important that this be allowed to evolve. In doing so, the adolescent is given the protection and security needed to discuss grief with the control she needs in order to assimilate her grief with all other facets of her life.

Conclusion

The issues of death and dying are powerful ones evoking feelings in everyone including professionals. This emphasized the need for specific staff training to help staff deal with its own feelings as provoked by their clients.

Although we are considered a technologically advanced society, the taboos dealing with death and dying are just as strong, if not stronger, than in the past.

Our Mini-Course on Death and Dying reaffirmed our belief that through death education, an adolescent can come to grips with the issues of death and dying.

The project will continue to focus on treatment for the grieving adolescent and his family. The area of greatest expansion will be in death education. Here, the focus will be to expand our service area. In the future, we hope to offer our mini-course on Death and Dying to other public and private schools in the community and nearby suburban areas. We plan to offer our services as consultants and trainers to other social service agencies, schools, religious groups and any other organizations where there is a concern about the issues of death and dying.

Andrea, age 20, sought counseling on the first anniversary of her mother's death in order to work through a number of unresolved issues. Her primary concern had to do with the anger and betrayal she still felt toward her father for not telling her of her mother's prognosis. She felt this anger was inhibiting her in relating to her father as well as in forming other intimate relationships. Her skill in art helped her graphically share with the worker visions of her family relationships as well as that of a mother-daughter relationship that was once vibrant and now was dead forever. She progressed through the stages of grief as one would predict and after three months terminated counseling. In terminating, she said to her worker that "now I feel in control of my feelings. I know that the grief process is cyclical and will always be that way. My mother will remain alive in my memory the rest of my life. However, I no longer am in constant pain when I think of her."

The Andreas of the world are many. Some cry aloud, others weep silently. Some openly recognize the grieving process which is engulfing them; others react only through symptoms which cloak the denial. Some are able to piece the puzzle together again, recognizing that they will never be the same. Still others will spend their lives trying to be what they once were. Shakespeare referred to this in *Hamlet,* stating "He jests of scars that bare no wounds."

No matter how diverse the reactions, the process is ultimately the same, the end result being to successfully complete grieving. To understand this process we must commit ourselves. This commitment must be to understand our own hurts and reactions. It

must also be to the understanding that through the expressions of their hurts we can serve vital roles in helping people achieve peace. With this commitment we truly acknowledge death, dying and grief: the last psychic barriers.

Bibliography

General Information

Brim, Freeman, Levine & Scotch, eds., *The Dying Patient.* New York: The Russell Sage Foundation, 1970.

Carse, Dallery, *Death & Society.* New York: Harcourt, Brace, Jovanovich, Inc. 1977.

Kubler-Ross, Elizabeth. *On Death & Dying.* New York: Mc Millan, 1969.

Kubler-Ross, Elizabeth, ed., *Death: The Final Stage of Growth.* New Jersey: Spectrum Brooks, Prentice-Hall, 1975.

Prichard, Elizabeth. *Social Work With The Dying Patient & The Family.* New York: Columbia University Press, 1977.

Schoenberg, B. Carr, A., Peretz, D., and Kutscher, A., eds., *Loss & Grief: Psychological Management in Medical Practice.* New York: Columbia University Press, 1970.

Schoenberg B. Cair, Kutscher, Peretz & Goldberg, eds. *Anticipatory Grief.* New York: Columbia University Press, 1974.

Schneidman, Dr. Edw. *Death: Current Perspectives.* Palo Alto: Mayfield Publ., 1976.

Children

Cook, Sarah. *Children & Dying.* New York: Health Sciences Publishing Corp., 1973.

Furman, Erna. *When A Child's Parents Dies.* Yale University Press, 1974.

Grollman, Earl. ed., *Explaining Death To Children.* Boston: Beacon Press, 1967.

Grollman, Earl, ed., *Talking About Death: A Dialogue Between Parent & Child.* Boston: Beacon Press, 1976.

Jackson, Edgar. *Telling A Child About Death.* New York: Channel Press, 1968.

Stein, Sara. *About Dying—An Open Family Book For Parents and Their Children Together.* New York: Walker & Co., 1974.

Funerals

Draznin, Yaffa. *How To Prepare For Death: A Practical Guide.* New York: Hawthorn Books, Inc., 1976.

Editors of Consumer Report. *Funerals: Consumer's Last Rights.* W.W. Norton & Co., 1977.

Adolescents

Bernstein, Joanne. *Loss and How To Cope With It.* New York: Seabury Press, 1977.

Mannes, Maya. *Last Rights.* New York: Wm. Morrow & Co.