

Anticipatory Grief, Death, and Bereavement: A Continuum

Austin H. Kutscher

It has been said that there are two things that man cannot face the sun and his own death. Yet, from the very instant of birth, we are on a long, it is *hoped*, trajectory toward death. Notwithstanding, all too few of us realize that a life is filled with major and minor preparations for death. There are constant *superficial* losses whose value in the process of this preparation should not be underestimated. The loss of a job, even voluntary movement from one job to another, loss of job seniority, loss of social status, loss of financial security-all are certain, less evident, examples of factors in this preparatory process. How many children survive their first haircut without tears? How many long-haired youth today dread, with accompanying and often extreme emotional conflicts, the parturition from this possession? And speaking of parturition, all are aware of the postpartum "blues," which often are seen to follow childbirth, and the sometime devastating effects on many young mothers. All of these preparatory losses can be accompanied by and complicated by evidences of grief, both anticipatory, prior to the loss, acid consequent, following the loss.

Therefore, it has been concluded by some, Dr. Arthur Carr, for instance, that these losses prepare the human being for the *greater* losses in his life, the deaths of his loved ones and, finally, the loss of his own life. As caretakers in the economy of a human's being, we should theorize about his ability to *accept* these losses through certain adaptive processes which include anticipatory grief and the work of bereavement; and we should try to affect the psychosocial consequences and patterns of his recovery from them at the same time that we also assist our dying patients to the boundaries of mortality. Death must be accepted and faced-the death of the individual and the death of the loved ones who predecease him.

When a fatal illness is diagnosed, as death approaches, and after the patient's death, there are many who are involved in the care of the patient, as part of his trajectory: his family, the nurse who tends him, the physicians who treat his illness, and the minister and social worker, among others, who offer spiritual guidance and counsel. In addition to the dying patient, all of these important role players, some to a greater and others to a lesser extent, usually pass through stages of one or another form of grief and bereavement and/or deal with the emotional problems of terminal care by various defense mechanisms, such as denial. In trying to conceptualize this, the context of the title of this discourse is offered, to wit: the continuum of anticipatory grief, the dying of the patient, the death as experienced by survivors, and bereavement.

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According to Dr. Elisabeth Kubler-Ross, in her book *On Death and Dying*, the dying patient proceeds along a path characterized by various stages until hopefully, but far from always, he reaches the point, or stage, of acceptance. These stages are (1) denial and isolation-failure to acknowledge the facts, disbelief in the face of overwhelming medical evidence, and a compulsion to be alone, to isolate himself, submerged in the depths of depressed and anxious thoughts; (2) anger-it can't be true, someone is lying, the doctors don't know what they are doing; (3) bargaining-if I do this, it won't be so; if I do that, perhaps something heroic, there will be a postponement of what seems to be inevitable; (4) depression-the sense of great loss; the reduction of the self-image; the realization of one's own shattered vulnerability and mortality; stress over the impact of medical expenses that go on and on; worry over the family at home; the realization that soon all will be lost, that the "me" will be gone from the scene; that death must be faced; and finally, if so, blessed; (5) acceptance--the inevitable will come no matter what is done; it must be faced by "me"; all will be lost; I do not know what will follow, but so be it: I have lived my life and tried to do my best.

Grief is the phenomenon of human behavior in survivors which accompanies loss; and its most striking effects are apparent when a beloved figure departs from life. The classic study of grief reactions was written by Dr. Erich Lindemann, who observed and treated both the victims and their survivors following the tragic Coconut Grove nightclub fire that took place in Boston in the 1940s. According to Lindemann, grief is a definite syndrome with somatic and psychological symptomatology, although medical definition may not recognize it as such. The most striking characteristics are weeping, a tendency to sighing respiration, complaints about lack of strength, feelings of physical exhaustion, digestive disturbances (such as inability to eat, repugnance toward food and/or abdominal discomfort), and so on. (The bereaved may demonstrate a sense of unreality and detachment and may be intensely preoccupied with the image of the departed one. Guilt concerning acts done or not done may plague him; accompanying this guilt are extreme feelings of irritability and anger expressed toward others or toward the deceased. The bereaved person is frequently restless but unable to initiate meaningful activity. Even in the performance of his daily routine, he finds the smallest effort almost beyond his energies and capabilities. Depression, agitation, and insomnia aggravate his physical and mental status.

Frequently, however, grief may have found its fullest expression before the death of this loved person. Its effects strike the bereaved-to-be at the moment the hopeless prognosis is pronounced, as he becomes aware of the truth of the situation. Therefore, the process of mourning begins long before the significant loss. It is contended here that during this period of anticipatory grief, the bereaved-to-be passes through some parallel, if not identical or synchronous, stages in relation to the dying patient (stages which would be, positively identifiable if accorded similar and adequate study): He denies and disbelieves the medical evidence; he isolates himself, fearing that a sharing of his

thoughts and doubts will only aggravate his torment and that of the dying patient, and other members of the family. lie is angry-perhaps at the patient who hadn't taken care of himself" and who is going to leave him to face the world alone, perhaps also to raise a family alone; or maybe at the doctors who refuse to do enough, or who are incapable of doing enough, or who may, lie thinks, be lying to him or who are inordinately brutal in disclosing the facts; or perhaps lie is angry at the nurse who brushes aside his agonizing questions because it is not in her province to answer them, or who is agonized herself by them and shields herself by denial, or who never seems to be around when she is needed, or who seems to be adding to the patient's discomfort when she fails to respond immediately to his ring-or perhaps his anger is directed at God; or various combinations of these and a host of others.

The family member, in this context almost always a spouse or a parent, begins to bargain: If I do this, maybe pain will disappear, maybe even my loved one will be healed; if only I pray, hard enough; if I perform some other demanding effort, this misery will go away and life will continue as before. He becomes depressed by thoughts of the present, by facts and fantasies of what the future will bring in suffering for all concerned-both during and after the course of the illness; he finds that lie cannot function, cannot summon up either his emotional or physical resources to face each clay as it comes; and so he is anxious and depressed; lie grieves-even mourns. Finally, hopefully, lie accepts the facts: death will come; it must and will be faced; and I will be left to do as best I can in the future; there is no choice, and I must do what has to be done. And-eventually-I too will face my own mortality: will I and how will I be able to accept that?

There appears to be a timetable of grief, oriented to the date of the onset of a fatal illness as well as to the date of the loved one's death. And this timetable relates the period of grief to some undetermined finite period of time. The presence of grief in anticipation of the loss, both in subtle and in pronounced ways, alter the trauma of the aftermath. When death has been prepared for by those who will survive, these bereaved may more readily find their way back to normal functioning. The contention here, requiring intensive study, is that there is a kind of symmetry and replication of effects: the more the anticipatory grief reaction before the loss, the less the bereavement effects following it; the less the anticipatory grief reaction before the loss (as must be inevitable in cases of sudden accidental death or death from an acute myocardial infarction or heart attack), the more the bereavement effects after the loss. Anticipatory grief creates an atmosphere, however ineffable, of adjustment to the potential loss; and so, to continue our hypothesis, then, is not anticipatory grief in its most simplistic course and form a generally repressed projection backward of bereavement itself?

The physical symptomatology of grief is most apparent during the bereavement period. The bereaved person presents a multitude of symptoms, as Lindemann and more recently Dr. Paula Clayton have related. Further and more recent studies, by Dr. Dewi Rees in Wales, Dr. C. Murray Parkes in England, and Dr. David Maddison in Australia, have also produced data which indicate a greatly and clinically significantly higher morbidity rate among the bereaved (particularly following the loss of a spouse and especially in the older age groups) and, more importantly even, a higher rate of mortality during the first six months of bereavement-tapering off thereafter. Neglect of the self, for

instance, may play some part, but there are some disease processes that cannot truly be related in such a manner, among them perhaps even cancer. It is contended here that parallel studies of anticipatory grief would likely reveal findings comparable in one of many such aspects.

Emotionally, both the patient's attitudes and desires and those of the bereaved-to-be may change from day to day: now lie may want to hear the truth and talk about it; tomorrow he may detach himself from it and/or deny it-depending on the stage achieved-and the changes of patient and family may be synchronous or may not. Not at all unrelated to the above, a new fact or sign or happening-and interactions involved-may occur, particularly within the cold walls of the institutional setting, with complicated emotional outcomes for all involved.

It is documented fact that most people today, in this country, die in hospitals and not at home (as was more often the case in the past). The hospital represents scientific achievement, the hope for cure with new and remarkable medications or machines, or, at the least, a dream of prolonging the life of a beloved one. But hospitalization in itself causes separation; separation results in anxiety; separation anxiety in turn further reduces the contact of both family and friends with the patient and, in so doing, increases everyone's anticipatory grief reaction; and the (lying person, detached from his familiar surroundings and unable to be a vital member of society, goes through this period in a most extreme state of anxiety, suffering his own highly specific form of separation anxiety and anticipatory grief.

The patient may have complaints, but they frequently mask what his real complaints are-among many others, fear of death, distrust of those who, he often rightfully feels, may be concealing facts or at least something from him, and so forth. He truly has the right to grieve his own dying but is seldom given the opportunity to express his feelings and concerns. lie usually finds himself being abandoned as his condition deteriorates; the living has already "written him off." He becomes the central figure in a great "conspiracy of silence"- forbidden to voice his fears and lying to concerning his condition and prognosis. The (lying patient nearly always knows the truth but often doesn't know whether his kin have actually been told the worst. In the process, lie may become antagonistic to them or, in many cases, may try to protect and shield his loved ones from the knowledge that lie has. And this brings us to that widely debated question: Should the patient be told the truth, that death for him is imminent?

Although we have been debating this subject for decades, from the above it may be surmised that I think that this may actually be the wrong question. The question to be coped with should really be: How should we deal with what we must assuredly assume he "knows" or has discerned?-what Reverend Robert Reeves describes as the "moment of truth" between the patient and his bereaved-to-be.

First of all, let it be understood that the nurse often talks the most with the patient and is in the best position to "read his signals." Her counsel should always be considered as extremely relevant. The life style of the patient should be considered-how lie handles trouble, reacts to bad news, responds in a crisis. And the life style of the

person in attendance who does the "telling" -the doctor, family member, or pastor-is also a factor which will profoundly affect the patient's future relationships with all those about him. And let us not forget that these caretakers who themselves are often desperately anxious about death, including their own, whether consciously or unconsciously, may erroneously convince themselves through denial mechanisms that the patient does not know the truth-or want to.

Most patients actually seem to fear the process of dying more than the unknown quantity, death. Yet, if those who will mourn his death would share their feelings with him in the living now, if emotional expression rather than emotional repression were to be allowed, many fears could be allayed; for many more, the terminal days could be a time for a kind of exquisite loving, sharing, and planning, and anticipatory grief for all would take on its most useful form and beneficent qualities. When there has been a free exchange of thoughts and emotions between two married people, or parents and a child-under these circumstances, the survivor is left with a substantial foundation on which to rebuild his life, a product of the positive effects of anticipatory grief, and with memories which become supportive during the days of sorrow and bereavement which follow the death. All such experiences represent a catharsis that ultimately allows the one to accept his own death with less fear (because he knows that he is loved and will not be abandoned) and his survivors to face the future with greater strength and a more suitably adjusted and positive life pattern. Hence, let us recapitulate the continuum of anticipatory grief, lying, and bereavement, well or badly enacted, as suggested in the title of this essay.

But too often the caretakers delude themselves into what I called above "tire conspiracy of silence." The terminal patient is shielded from the truth. True, not all patients do want to know, and not all should necessarily be told; and -if denial of the truth is the only way a patient can handle his dying, then he should be allowed his denial. But the greatest cruelty is inflicted when the patient *does* want to know and is not told. Observation has revealed that most patients crave an opportunity to ventilate their thoughts and feelings. Only in recent years, however, through the work of Dr. Herman Feifel, Dr. Elisabeth Kubler Ross, and Dr. Avery Weisman, among others in the field of psychiatry and psychology, has the value of allowing the dying patient to ventilate his fears been appreciated. Perhaps above all, though, both for the patient and for his family, hope should never be utterly destroyed. The treatment plan should always be projected beyond the presumed life expectancy, recent conceivably hope-engendering developments in medical research can be discussed, and so on-so that at least a glimmer of hope never dies. And even when hope for survival is only a very dim all(] fading light indeed, a whole new series of realistic achievable goals can effectively be introduced for all involved so that life may be lived to the very end. Such realistic goals can be, for example, strong reinforcement of the already acknowledged and existent love of a spouse, the summoning of strength to live until a grandchild is born, the settling of unsettled and hence troubling personal affairs, the resolution of family difficulties and intensely personal differences between the dying patient and surviving members of the family, reconciliations, and perhaps most important of all, in some

instances, the hope of achieving what Dr. Ross has called "acceptance"-in the wake of which death with dignity can then be achieved.

In Great Britain, Dr. Cicely Saunders has established a "resting place for the weary traveler," the dying person, called St. Christopher's Hospice, a unique-and I should not perhaps, since she does not, even call it this-hospital for the terminally ill, where heroic measures are not taken to sustain life or prolong dying, where pain is controlled even as it starts, where (lying truly becomes a part of living as the very walls of the hospital are breached to allow the family to enter at will, where a staff of compassionate and believably dedicated (in some instances highly religiously dedicated as well) people has been enlisted to support and tend the patient and permit him to die in dignity.

Such professionals, our caretakers, both on tire scene and behind the scene, are involved not only ill their professional capacities but also personally and emotionally with anticipatory grief and, thereafter, to some degree or other, with actual bereavement. How many-or perhaps we should ask how few nurses and physicians don't reach a point of emotional overload during periods when it seems that one patient after another dies in spite of all their combined and/or individual efforts to save or extend a life? And so, by way of answer, we pose some further queries: Why do some professionals avoid service in wards where terminal patients are moved to die? Why do so many others tend to abandon the patient as his condition deteriorates, to visit him less frequently, to perform only those acts which treat his primary illness, to hustle and bristle in and out of the room as rapidly as possible, avoiding conversation which may prove to be embarrassing and avoiding answering questions, fearful that their own acknowledgment of the patient's psychological distress, anti *their own*, will bring forth tears-maybe even their own? (Somehow or other, incidentally, we regard crying in ourselves and others as unworthy, unmanly, or an inappropriate reaction-when such *is not* the case at all.)

I would like at this point to offer some succinctly expressed words to serve, it is my hope, as a few effective tools for all who care for or surround the dying patient and his family.

1. The caretaker's chief obligation is to provide what Dr. Avery Weisman has so imaginatively called "safe conduct" for the dying patient.
2. The primary suffering of the patient is handled by those who can relieve the physical symptoms of his ailment, especially his pain or his disfigurement; but his secondary sufferings-the loss of self-esteem and body image, the fears of abandonment and separation, the anxieties and feelings of hopelessness-must also be treated-by anyone who can function well in this capacity.
3. The reactions of particularly close family members should be scrutinized in order to help them and to enable them, those who are losing the most, to also give the most in support of the patient's secondary suffering; and in so doing gain a measure of peace themselves.
4. High-risk family members, those adjudged to be most prone to suffer at some point from pathological and extended grief reactions following their loss, should be singled out for special counseling and treatment.

5. The patient should be allowed to make *as* many decisions regarding his own treatment, even his own manner of dying, as is consistent with his welfare, not heeding needlessly only the emotional welfare of his family or especially that of his caretakers.
6. Communication should always be maintained among all on the scene; self-esteem should be reinforced.
7. There are many, including especially family members, who can help the patient achieve his final goals—not only the physician and the nurse. Professional credentials are often less important than a person's ability to be present, to be readily available, to be alert, to be compassionate and willing to be on the team. And, touch the patient; let there be someone to hold his hand, literally, if possible, to the end.
8. The team should include, among others, the family, the clergy, social workers, psychologists, and psychiatrists *as well as* physicians and nurses.
9. The new ethics presented by the ability to transplant organs, or sustain failing ones mechanically, compels the physician to be the prime decision maker, the one in whose hands the "buck stops." But, nevertheless, these decisions and ethics involved pose profound and emotionally traumatic problems for the physician who he would be well advised to share with the family, clergy, or others.
10. The family should always be aware that to the physician, regardless of his concerns about the patient, one death in particular is of even greater concern to him: his death.
11. The bereaved will have to deal retrospectively with the trauma of the deceased's illness and death, and he may be haunted by memories, even guilt, even anger. Caretakers must be available to contend with these also.
12. The passing of certain cultural and ethnic rituals, such as portions (at least) of the formal funeral, sitting *shihah*, and the wake, has probably been detrimental for the family as viewed sociologically and can hinder acceptance of the loss and the bereaved ability to continue as a functioning human being. These rites and the attendant opportunities for loving companionship and self-expression often offer great emotional support to the bereaved (even if many do not choose to acknowledge such benefits because of often unfair financial burdens imposed by some funeral directors).
13. The grief experience can be transformed into a most meaningful and productive one through emphasis on the concepts and ideals of *creative* grief. The energies expended in grieving can be channeled with enormous productivity into good works or deeds, service to others in distress, devotion to tasks left undone by the deceased, etc., rather than dissipated in an unstructured and self-pitying melancholia.

But these are not, by any means, all the answers. We have scarcely scratched the surface. Even the few statistics drawn upon may be viewed dubiously because we are just beginning to gain insight into what to research, and such research has just barely begun. One more observation is in order: Our efforts in this field may need reappraisal, since it appears that for every fifteen investigators working with the care of the dying patient, there are probably only three dealing with bereavement, and only one with studies of anticipatory grief. This is discouraging to relate, in the opinion of many of our most informed workers, such as Mrs. Ruth Abrams, since the possibility

for the most effective interventive medical action related to bereavement perhaps lies in the improved management of anticipatory grief.

We have turned around and around in our continuum: the classical picture of anticipatory grief, the (lying experience *and* its management, and the final facet, bereavement. Not have we neglected to mention our own psychological trauma at the thought of the (lying "me." It should be apparent, then, that we have come full cycle and have, perhaps, even reached certain conclusions: (1) that our lives are spent in preparation for the bereavement which our great losses bring, including the death of "me"; (2) that there are doubtlessly stages of anticipatory grief which in one way or another parallel Dr. Ross's stages of dying-in a complementary fashion, sometimes and best of all in synchronization but sometimes out;(3)that, if we can achieve some degree of real synchronization we can make the bereaved-to-be function more satisfactorily as members o the team that cares for the terminal patient; (4) that the mortality and morbidity of bereavement may well, with proper research and through the use of proper investigative expertise, be demonstrated in anticipatory grief, thereby reinforcing the decision to intervene at this point; (5) that it is logical to conceive of anticipatory grief as a repressed projection backward of bereavement; (6) that it would follow, then, that bereavement is the logical aftermath of repressed anticipatory grief; (7) that there is a symmetry and core of replication between anticipatory grief and bereavement from which it might well be hypothesized that the greater and better managed the one, the less of the other; and conversely, the less of the former, the greater the latter; (8) that these are challenging and critical areas for research.

Man cannot face the sun, but he must nevertheless face his own death, if lie is to live. He must accept death as a part of his life-as a prerequisite for his enjoyment of and formal acceptance of the full beauty and tragedy of life. Just as it is possible for the dying person to achieve acceptance of his own death and die in dignity, so too the living who are bereaved can, with help, be brought to accept a life in which death is an integral part. The challenge to us all is at least twofold: Where is our place in the continuum at any time? How can we be effective as clinicians, as scientists, and as human beings?

