HOW IS THE DEATH OF DOCTOR CLARK TO BE UNDERSTOOD

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Understanding The Death of Barney Clark

Introduction.

The impact of any death cannot be discussed in some global, overarching manner, but must be viewed from a number of different perspectives. The failure to keep these frameworks of reference separate in thinking about death and the care of the dying leads to much confusion. Consideration must be given to the dying body, the person who is dying, the two person relationships, if any, of which the dying person is a part, the patient's family, the community, and sometimes -- as in the case of Barney Clark -- the nation and the world at large.

Each of these levels on which a death has an impact is distinctly separate from the others, and each -- despite their obvious and necessary inter-relationships -- requires different information and kinds of understanding in order to act effectively. The death of Barney Clark illuminates each point I have made. Despite the seeming abstractness of this approach to understanding the care of the dying and the impact of a death, the death of Barney Clark makes clear the very practical consequences of their disregard and of our ignorance in their terms.

Before going further, I believe it is necessary to make it clear where I stand in the regard to the artificial heart. There is no question that the same amount of money that is being used to produce and implant the artificial heart could improve the health of many more individuals if it were employed in a program of preventive services. But that, and many other objections that are raised to the advance of high technology are, to me, besides the point.

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Technology advances whether one agrees or not. One can turn aside or join, but as has been frequently noted, technology has its own imperative. Personally, I enjoy it. However, it seems reasonable that a new advance like the artificial heart, as discontinous from previous capabilities as it is, should not be deployed in technological or scholarly isolation, so I sincerely applaud the openness of the Utah team, and their willingness to explore so many issues connected to the device.

Unfortunately, when new technologies are developed, the focus of intellectual attention comes to be almost exclusively the technology itself rather than its impact on the world around. For example, the artificial heart is implanted to avert a patient's death. But despite the attention death or its avoidance receive, whether the patient lives or dies may turn out to be only one of the fundamental issue raised by the implantation of the heart. Consideration of problems surrounding the care of the dying patient, or of death itself -- such as the levels I noted and on which I will be expanding -- require as much innovative thinking, research and development as the heart implant itself. Perhaps the time has come to require an "impact statement" before radically new technologies such as this are further implemented in order to prepare the society for the widespread effects of the new advance.

The Body.

Although medicine concerns itself with the human body, its knowledge and its methodologies are most often directed at individual organs or subordinate levels of organization such as a cells or even molecules. Except in the minds and actions of individual physicians responsible for patient care, rarely is this biological information integrated into knowledge about whole bodies. Put another way, bodily function, or even single organ function is not frequently viewed as a whole. This deficiency of understanding has had little adverse effect in the development of artificial organs before the artificial heart, because despite the name, organs were not being replicated, biological functions were. For example artificial blood is not "blood" at all; it is artificial oxygen carrying capacity. Blood, as we all know, has many other functions besides oxygen transport. Similarly the artificial hip is not a hip, it is not even a joint, it is merely the function of articulation. Joints also have tendons, muscles and capsules. Even the artificial kidney merely replaces one function of the kidney -- a permeable membrane in an exchange bath -- the natural kidney performs other tasks as well. Generally speaking, then, success has followed where a function has been replaced.

In listening to the manner in which people, including doctors, talk about "artificial organs", one might come away with the belief that all the organs just sit there "doing their own thing" and from that concert of individual actions, the function of the whole organism occurs. I was led to believe that the same viewpoint was (at least initially) held by the Utah team, because when Dr. Clark died, it was reported that his artificial heart had worked fine, but that his kidneys and his lungs did not hold up because they were so diseased prior to the implant. While I have no question that Barney Clark's kidneys and lungs were impaired after his long history of congestive heart failure, the failure of his body after the implant can be attributed to a failure of the implanted heart. It might have been a great heart while it was sitting in a box, or on a test bench in splendid isolation, but it was not a good "Barney Clark Heart." To be a good "Barney Clark Heart", a heart had to have a very low cardiac output. Since we usually consider a good heart to be one with a high output, how is it that a good "Barney Clark Heart" should have a low output? Because all the organs of his body had adapted to the low output of his chronically failing heart -- so had Barney Clark himself -- and that adaptation takes time to change. If a new heart with the capacity for a high output is implanted, the "normal" output will have to be achieved slowly enough to give the other organs time to adapt -- and probably after starting at the output of the heart that has been replaced. Anecdotally, we all know about how slowly the body adapts to the return of function of a previously diseased part. That adaptation is called convalescence from the "deconditioning" that accompanies illness. But "deconditioning" isn't deterioration except from an organ point of view. From the whole body framework of reference, it is adaptation to an enforced state of illness. After all, it would not do to have peak muscle strength coupled with a mind bursting with eagerness in a body that has a heart that cannot exceed two liters of output.

The problem of "fitting" the output of the artificial heart to the system in which it is being implanted (and vice versa) will, predictably, be present every time the device is employed. Therefore, in the course of the care of the next patients who receive artificial hearts, information can be obtained that will lead to an understanding of how whole bodies adapt to the change of a part. Such research will be important in itself, but it might also serve as a badly needed model for research on whole organisms. General systems theory has provided a manner in which to view problems of this sort, but a methodology robust enough to good systems research in humans still is lacking.

Another practical consequence of not realizing that the function of the artificial organ must be fitted to the system into which it is implanted has to do with what the patient and or the family are told about the reasons for difficulties. As noted above, it was said that Barney Clark's new heart did not do as well as it might because of pre-existing pulmonary disease. That chronic obstructive pulnomary disease was attributed, correctly I am sure, to his prior cigarette smoking. But the implication is that the failure was really the fault of Barney Clark and his "bad habits." It is my opinion that patients are all too ready to take the blame for failures, blame that their families come to share. The feeling of culpability remains long after the death and long after the words have left everybody else's mind. Attribution of blame is best left unsaid.

The Person.

Dr. Barney Clark died, not his body. Further, a sick Dr. Barney Clark died, not only Dr. Barney Clark who happened to have a diseased body. Although both statements may seem to be truisms, they contain distinctions that are often forgotten. Virtually everyone who has ever witnessed death or cared for the dying, has tried to solve the puzzle of what disappears in the change of state from alive to dead. The attempt to make of the transition a "simple" biological matter has led to some strange writings. For example, Marie-Francois Bichat, in Recherches Physiologique sur la Vie et la Mort published in 1800, examined the changes that occurred post-mortem in order to understand better what happens at death and the order in which the organs die. The book is an example of the sterility of the enterprise. None the less, in the application of the recent advances of medicine, it often appears as though it is merely the body that doctors must save from death.

In fact, of course, life makes a difference to persons. I presume that Dr. Clark underwent the discomforts and dangers of having the implant because he wanted to live rather than because he wanted to avoid dying. The distinction is important because it is often difficult for physicians -- particularly young doctors -- to realize that there are things worse than death. When Jehoveh's Witnesses refuse transfusions, even though death may be inevitable without the blood, they are not choosing to die, they are avoiding the far worse fate (to them) of having their souls condemned to everlasting purgatory because of the sin of receiving the blood. When the patriot says, "give me liberty or give me death," he is implying that life without liberty is not worth living. Similarly, when a chronic dialysand decides to discontinue dialysis despite the fact that death will follow, that person makes the choice that an existence of continued dialysis is intolerable, not that death is good. It is crucial to understand this for many reasons, but one of them is the confusion over the moral difference between starting and stopping a life prolonging intervention. We are all aware that Dr. Barney Clark had to give permission for the implantation of the heart. If he had wished it discontinued after a time, he would not be "committing suicide," he would be withdrawing permission for the intervention. Presumably because life as "Barney Clark-plus-artificial heart" might have become more problematic than death as Barney Clark.

The forgoing is the reason that many who regularly care for the dying believe that death may be important, but it does not matter as much as other things -- living, for example. Such statements often sound strange to the healthy. After all, being not-living seems to be the same as being dead. Aside from the biological obviousness that if you are alive you are not dead, living is not at all the same as (merely) not dying. The focus of attention for the living (as it is meant here) -- especially those for whom the threat of death is immediate -- is on the present and the important things contained in the present. Most healthy people spend very little time in the present, dwelling instead on future hopes, anticipations, fears, distresses and guided more by their past than their present needs. It is difficult to get healthy individuals to focus on life in the present, which often sounds like some kind of hocus-pocus. But the very sick understand, or can be helped to understand very much more easily. Thus far, at least, only sick people are candidates for artificial hearts and so these concepts apply to them. So it is essential that in caring for those who receive heart implants, the staff place their emphasis on living, not on the avoidance of dying.

What I said in the previous paragraph may be denied by the fears for their continued existence that the very sick often exhibit -- indeed, their tendency to have many fears is striking. However, it is in the management of those fears by doctors and other caregivers, that the very sick are freed to savor life in ways that make the sickness endurable -- or better. But to deal with the fearfulness of the ill, one must realize that the sick are different than the well. They are not merely well people with a sickness appended to their sides, but in their relation to themselves, objects, people and relationships, as well as their mechanisms of thought, they differ from the healthy. Knowledge of the characteristics of sickness -- no matter which disease has imposed the state -- are important to the care of heart implant recipients whether they live or die. Such characteristics cannot be considered the "psychological" aspects of the case, to be dealt with by psychiatrists or social workers, but must be understood as central to understanding how to deal with the diseased body, as well.

In discussions such as this, reference is often made to the problems raised by the mind body dualism. It is true that Cartesian dualism has outlived any utility it may have had, but here I am speaking of the body-person distinction. We all think of ourselves as persons but the category of person has trouble finding a home (except in the law). Clearly a body is not a person, because person includes body. Mind is not person, either. Person is a larger category than mind. Further, the notion of person -- what it is to be a person -- is different in different cultures and historically. See how individualized -- me, myself and I -- the idea of person is now as compared to (say) the turn of the last century. The distinction between body and person is both clarified and its importance underlined by the problem of suffering.

Understanding the Death of Barney Clark

Medicine's goal is often believed to be the relief of suffering. Indeed, the problem of human suffering is central to many theologies. But there is little understanding of what the word suffering means. If one searches the medical literature one quickly notes that suffering and pain are usually linked -- as in "pain and suffering." But it is a simple matter to demonstrate that pain and suffering, although they are often found together, are discrete phenomena. For example, suffering may be caused by severe pain. But I have recurrent renal colic, which, while very painful are not a source of suffering to me. I know what is causing the pain and that it can be relieved. Childbirth can be very painful, but modern methods of ameliorating the pain focus not on its absolute ablation, but on giving the mother control over her own childbirth. On the other hand, patients may suffer greatly from rather mild pain if its source is unknown but suspected to be dire. Similarly, never ending pain may cause suffering even though it is not severe. (Doctors and healthy people do not know much about this because people with endless pain learn not to say anything -- what can you say after you have said it hurts.) The evidence that is is not the pain itself that causes the suffering is that suffering may be relieved in the forgoing situations by; naming the pain and showing its source to be benign, by showing the patient that the pain can be controlled. In this latter instance, after patients are aware that their pain can be relieved, they are often quite willing to tolerate it rather than the side effects of the drugs, and without the former suffering. The distinctness between pain, or other physical symptoms, and suffering is highlighted by the fact that one can suffer without any physical symptoms -- watching one's child suffer, for example. I could adduce more evidence to show that suffering can arise from the loss of intactness, or the threat of the dissolution of person in any of its many dimensions. And that suffering can be relieved if the threat is ameliorated or intactness restored. But the basic point that is relevant here is that bodies do not suffer, persons suffer. If this is the case, then it is necessary to understand the nature of person in all its dimensions which include; personality and character, the lived past, the family's past, the impact of culture and society, relationships with others, roles, relationships with the body, the unconscious mind, day-to-day behaviors, the political existence, a believed in future, a secret life, and last, but by no means least, the transcendant dimension of being a person. It is in relationship to these aspects of being a person that suffering occurs (and may be caused by medical intervention as well as disease) and in relation to them that suffering may be helped. Death is not important to bodies, only to persons.

We have seen, thus far, that the scientific view of artificial heart implantation deals primarily with units of the body -- organs and their constituents -- not with whole bodies or with the persons of whom the body is a part. This framework of reference can compromise the success of an implant unless the function of the artificial heart is "fitted" to the whole system of which it becomes a part. Further, the success of a procedure has to do primarily with the sick <u>person</u> who receives the implant, not merely that person's body. We have also seen how little is known, in a systematic manner, about persons. But it is important to realize that this lack of systematic knowledge of persons is not something that can be remedied by further scientific exploration of the subject (now that we realize how important it is). In fact, <u>no</u> modification of the current scientific viewpoint will or can encompass those aspects of persons that we might all agree are important (perhaps using ourselves or the Golden Rule as a guide). Witness the emptiness of most discussions of "quality of life" when they occur as part of clinical or scientific papers. No method of science can produce systematic understanding of persons because no scientific methodology can be expected to discover what modern science does not consider to exist in the first place -- notions of quality (virtue or excellence) and value. Without such consideration of quality and value any concept of person is empty of meaning. Other aspects that are entailed by personhood, such as ambiguity, uncertainty, non-distinction, or even complex change over time, are also opaque to science.

<u>Ethics.</u>

The increasing consideration that the sick <u>person</u> (rather than merely the disease) has received in medicine has been paralleled by the growth of the discipline of bioethics. In fact, one of the basic roles of ethics in medicine has been to provide a formal structure through which respect for persons is expressed in research on human subjects, in the care of the dying, as well as in the every day diagnosis and treatment of the sick. Respect for persons has found its most concrete outward expression in the understanding that nothing can be done to any patient without his or her consent. In terms of the care of the dying, respect for persons leads us to the awareness that the dying person has the almost absolute right to be allowed to refuse treatment and even to choose his or her mode of death within the constraints of fate and the law.

Notions of respect for persons, however, are somewhat vague -- who, after all, would profess <u>dis</u>respect for persons. Thus respect for persons is rarely the key term used in discussions of ethics in medicine. Instead, reference is made to the importance of autonomy. Because being autonomous -- having the ability to exercise freedom of choice -- is only one aspect of being a person, basing ethics so heavily in autonomy suffers from the same fundamental defect as implanting an artificial heart based almost solely on knowledge of hearts (rather than whole bodies). I believe I can illustrate this defect by reference to the consent form signed by Dr. Barney Clark prior to the artificial heart implantation. Consent forms, as they are increasingly being employed in medicine, are meant to provide the information about the risks, benefits and alternatives to the procedure or treatment in question that would allow a prudent person to decide in his or her own best behalf. In order to meet this standard, the Utah Institutional Review Board apparently considered it necessary to require a consent form that was fourteen pages long! Further, Dr. Clark was to sign the consent on the occasion of his reading it (in company with his doctors who were to provide him with any further information that he might desire), and again twenty-four hours later. Finally, according to criteria established by the Institutional Review Board, to be a suitable candidate for artificial heart implantation, a patient had to be near death from chronic congestive heart failure. It requires little clinical experience to know that sick persons cannot read and correctly comprehend fourteen pages of technical information about the device that offers them their only hope of returning to life.

It seems reasonable to ask whether a hypothetical Dr. Barney Clark would have signed such a form, in an unknown place, peopled by faceless strangers, had he been sent there for a previously unknown kind of medical procedure -- in the state of ill-health we know him to have been. The reason it seems unlikely that Dr. Clark, or anyone else, would sign under such circumstances, is that the whole consent procedure is based on trust. Where trust is absent, consent -- informed or otherwise -- becomes extremely problematic. One knows this to be true because the information provided by consent forms is meant to reduce uncertainty and permit people to act in their own best behalf. The more crucial the action and the more dangerous the alternatives, the more intolerable uncertainty becomes and the more information that is required. But information can only be expected to reduce uncertainty if it is believable. To be believable, information must come from a trusted source. In life and death medical decisions, uncertainty can only rarely be reduced to zero -- there is never enough information, if only because the future is involved. In such circumstances, individuals resort to trust in others to solve the problem presented by ineradicable uncertainty. Expert others not only have more information and knowledge, both latent and manifest, but they are considered to have the ability to make decisions involving competing probabilities. Deciding who to trust is a personal matter; but it is also social. Trust depends on the mutual obligations and responsibilities each of us has in relation to others because of our roles and relationships within the shared matrix of culture and society. Thus, the consent form given Dr. Clark to sign, and which stands as a tribute to the importance we place on autonomy, underlines the inadequacy of the concept of autonomy.

In the simplest terms. There is _no_ autonomous, free-standing individual of the type pictured by currently dominant ethical theory. In the same manner, there is _no_ isolated piece of matter from mitochondria, to muscle to hearts, as pictured by science. However, ideas about "autonomous" individuals, and "isolated" matter have been extremely productive artificial constructions. Neither, unfortunately, is adequate to the artificial heart program. I am aware that despite the inadequacies of these concepts, there will be further progress because practical people generally discover practical solutions to practical problems long before they discover theoretical solutions. On the other hand, theory must ultimately change or in its pursuit of progress society risks being trapped instead in repetitive, boring newness. An example of what I mean is provided by those forecasts about the future of medicine which detail the new technology just beyond the horizon. New technology is new in the sense that a 1984 model automobile is new. Not in the more important sense of a new understanding of transportation that portends methods of transport that are currently unimaginable. The advances in theory that are required will show how autonomy is modified by the fact of other people, families, communities and society in general. For medicine, it is necessary to understand how a relationship with a doctor might promote, rather than limit the patient's autonomy.

The next levels -- two-person dyads and the family -- make even clearer the inadequacy of current concepts of autonomy as they apply to medicine.

Relations Between Two Persons.

In exploring the consent procedure in this case, one might get the idea that the Institutional Review Board believes that not only is Dr. Clark the only person who can decide what is in his best behalf, but that in some way he must be protected from interference in that choice by his doctors or the medical center. There are commentators on bioethics who would state, putting the case more strongly, that Dr. Clark and his doctors are adversaries. Since it is generally conceded that beneficent motives are fundamental to the medical enterprise, in the usual instance, any actions that might be interpreted by some as interference in Dr. Clark's choices, would be defended by his doctors as being in Dr. Clark's interest. In the bioethics literature, the derogatory term "paternalistic" is applied to physicians who think that they might know the interests of the patients better than the patients thermselves.

Somehow the charge of "paternalism" seems overly simple. Everyday experience suggests that on occasion, less swayed by physical symptoms, false expectations, inordinate desire, or unrealist fears (to name but a few of the influences that may cloud the judgement of the sick) others may know our interest better than we. It is also well known that physicians can, and frequently do, act in the service of their patients without putting themselves or their own selfish interests above their patients. The nature of the bonds between pairs of people that promote selfless concern for another are not well known in this era. In previous times words like selfless, trustworthy, honorable, altruistic, compassionate and similar moral descriptive language were taken to represent real traits by which the sick or the weak might be protected or cared for by others. These moral bonds have become the subject for distrust, and in their place there has been erected a structure of law and regulation designed to accomplish the same goals with less bias and greater protection from human foibles. Despite their advantages, these technical substitutes for previous moral bonds are formed around median standards of behavior which do not, I believe, promote higher standards. Cramped by a worldview that sees people as almost exclusively atomistic individuals, we remain suprisingly ignorant of the bonds that can form between two people and that cause them to behave well towards each other. Since the relationship between doctor and patient is such a bond, medicine is the poorer for the lack of knowledge. No regulation or consent procedures will protect the recipient of an artificial heart better than the obligations and responsibilities of those charged with his or her care. It is reasonable to explore what, in the environment of medical care (in this instance in The University of Utah Medical Center) promotes these bonds of responsibility, and what hinders them. In pursuing this subject it is interesting to note how little is known in any systematic manner. In fact, one will learn more from literature, particularly the romantic poets, than from the fields of psychology or the social sciences.

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The Family.

Husbands and wives are the two person relationships that first come to mind in the preceding context. But husbands and wives are not true dyads, they are members of a family. And a family, no matter how small, always presumes other people without whom there would be no family, at the very least those in the previous generation. Thus the family is always in debt to the past. In addition the family is always in thrall to the future because that is the expectation of families.

We are used, as a habit of mind, to consider the loss of a physical presence to be the phenomenon of greatest importance in any death, and in terms of the decedant that certainly must be true. But there are other changes that are as decisive and irretrievable. The death of an individual almost always changes the structure of a family. When Dr. Barney Clark died, his generation of his family died with him. His wife became a widow and his children lost their father. The social (and personal) status of each of them changed and that change is reflected in the way the world behaves towards them and the manner in which they behave towards themselves.

The kind of medical care a person received prior to and at the time of death influences the changes that take place in the family. It was common in 1961, when I started practicing, in order to reduce the pain of the loss of a loved one, to shield the relatives from as much of the unpleasantness of death as possible. The standard practice at the time leads one to deduce that received wisdom was that death is a permanent separation which should take place as cleanly and completely as possible, and that once the physical cleavage has occurred, the worst is over. Or, to put it more bluntly, dead is dead, let the living get on with life. Family members were often discouraged from long stays at the bedside during the patient's last days, although it was not rare for a spouses, parents or children to insist that they belonged there. The family was even more vigorously shielded from agonal sights and sounds. Young children were kept away from sickbeds, in general, and even more so from the dying. When families asked whether the children of someone about to die should be brought home from (say) college, it was often thought wise that the soon-to-be-bereaved stay away and attempt to lead as normal a life as possible. The aged were protected from the knowledge of the impending death of a loved one for fear of the risk to their well-being posed by the bad news. The words "dead," "dying," or "death," were rarely used directly, instead, euphemisms were employed. This further increased the distance between dying persons and their loved ones. These behaviors became popular at the same time that the scene of death shifted from homes to institutions. It should be noted, however, that twenty years ago, intensive care areas and very intrusive life sustaining or resuscitation equipment was absent or rare.

Current beliefs about these issues highlight how much things have changed. Present understandings focus on the importance of behaviors occurring at the time of the separation of the living from the dead. It is as though the closure of relations between loved ones can occur in special ways at the time of death that are not possible (at least in the same manner) at other times in the life cycle. Further, more and more people believe that when such emotional resolution does not occur at the time of death, the lack can never be remedied, and the pain of greaving will be greater. Statements such as, "I had a chance to tell my father I loved him, which was very important to me," are typical of this belief.

As a consequence of these newer understandings, it is increasingly accepted that the care received by the dying patient should facilitate the resolution of relations between the patient and loved ones. For this to occur, several goals must be pursued. The first is to allow a smooth and emotionally complete separation at the time of death. The primary step toward this is facilitating communication between patient and loved ones so that both patient and family know, as much as possible, what is the diagnosis and when death is to be anticipated. In the case of Dr. Barney Clark, there was no lack of information.

The physical setting also influences the opportunities for loved ones to be close to the dying patient. Consequently, increased length and convenience of visiting hours, open access of family to the patient's bedside, reduced intrusiveness of medical procedures and hospital bureaucratic concerns, can all increase the ability of the family to visit the patient. Although many of these are not directly controlled by the physicians, they have considerable influence in individual instances. The vital fact that must be remembered is that the well-being of loved ones is part of the doctor's responsibility in terminal illness. Naturally, there are limits to that responsibility, and problems arise when the needs of the family and those of the patient conflict. (I believe that in such cases the primary responsibility of physicians is to their patients. Here as in other circumstances, compromise and open discussion often allow conflicts to be resolved.) Doctors will help family members say goodbye in a smooth and fulfilling way when they understand the present belief that the family must be permitted to spend as much time as possible at a bedside, that saying goodbye is important for each loved one, and that whenever possible it is best that spouse, parents or children who wish should be allowed to be present at the time of death.

Unfortunately, many physicians view the needs of the family as obstacles to the essential activity of caring for the patient's disease. While family needs may, on occassion, intrude, in the case of the dying patient the physician must set new goals which include the well-being of the surviving family. Where the outcome is uncertain, as in experimental procedures such as artificial heart implantation, conflicting responsibilities may be more difficult to resolve. When a realistic chance at meaningful survival exists, current attitudes give the patient's body highest ultimate priority. In the instance of Dr. Clark, and in future artificial heart implantations, the community and the nation also have needs which are met largely through the media. When the needs of the family and the world at large are in conflict, it seems clear that the family comes first. Since the media frequently behave as though they are unaware of this principle, it must be reinforced by the physicians in charge.

In addition to facilitating a smooth separation from the dying patient, physicians should, as much as possible, help relieve survivors of the inevitable guilt that accompanies bereavement. Although the source of the guilt is unclear, its presence seems universal. Free-floating guilt seeks any event on which to fasten. Physicians have the opportunity to lessen the reality-basis of survivors guilt. The newly bereaved should leave the death-bed with the faith that they and the doctors have done the right thing for their loved ones. They should believe that nothing better could have been done, no better decisions made, no more consultations considered -- that, in a word, even God would approve of the actions taken. Physicians should help diminish opportunities for surviviors to blame themselves or the medical attendants. As was done in the care of Barney Clark, family members must be kept informed as the case progresses and be permitted to take part in decision-making whenever possible. Loved ones should understand the reasons for important medical actions and realize that physicians care as much about the relief of suffering as they do. The family should not be overprotected with undue optimism or false hopes. Rather, to the degree possible, they should be made aware of forthcoming risks and complications. Family rivalries often surface and intensify at the bedside of a dying parent. It is impossible for the doctor to solve the problems at a death-bed that have occupied the family for a generation. It is feasible, however, to insist that everyone be notified, that every family member have a chance to visit and say goodbye, and that everyone of the same family rank partake in, or have access to, the decision-making process, when possible. Great, and frequently thankless, diplomacy may be required in such situations, but it is better attempted than not.

While facilitating separation and removing as much grounds for future guilt as possible, the physician must take care not to overburden family members. Compared to obligations to a dying person, which may be perceived as boundless, loved ones may see their own needs as selfish, or worse. Limits should be placed on what is expected of family members, and on the degree to which they will be exposed to painful sights, smells and sounds. Because individuals vary in their ability to tolerate the physical unpleasantness of dying, there can be no hard and fast rules. One errs best on the side of protection, but then one should be as flexible as possible about the behavior of individual family members. The custom, followed in many hospice units, of giving the visitors one day off a week is a wise one and might guide physicians in their advice to the family. The aim is to avoid a spouse (or other family member) so worn out in advance, that no reserve is left to cope with the death, itself.

Like everyone else, the bereaved must organize experience according to categories that are consonant with culturally accepted views of reality. There are a number of things that are commonly experienced by the recently bereaved that are not encompassed by our culture's worldview. Thus, a bereaved spouse who feels an extremely strong sense of post-death presence -- exemplified by, "I would hear a sound in the bedroom and know she was calling me, that she needed something. Then I would go in, and of course she wasn't there" -- may consider it a mental aberration. The prolonged pain of loss experienced by the bereaved may be attributed by themselves and others to abnormal grieving. Similarly, the continued dependance of the mourner upon the dead person and his or her advice ("I think, what would he tell me to do") is often considered abnormal. When the bereaved find themselves experiencing the death and its after effects differently than they had expected or than is the culturally expressed "norm", they may become isolated from the group, find their sense of wholeness threatened, their understanding of events undermined and their ability to control the grieving process inadequate. These features, which are common concommitants of physical sickness may, in themselves, become a potent force in promoting illness in the bereaved person.

Physicians can be a powerful force in resolving some of the difficulties that arise when survivors' experiences cannot be explained by culturally acceptable categories of reality. Physicians have an important normalizing function. We commonly return patients to peace with their world by considering normal what the patient feared was abnormal. In the care of the bereaved physicians can serve the same normalizing function by validating those experiences which the survivor fears are abnormal, or even a sign of craziness. In addition, doctors who have had sufficient experience can provide the reassurance that for this culture (as for all others) there are realities outside of the shared categories of society.

In summary, physicians can reduce the stress of bereavement by the way in which they provide care to the dying person -- facilitating emotional resolution and separation, reducing the opportunities for guilt-producing behavior, and easing the physical and emotional burdens that accompany terminal illness. In addition, doctors can reduce the potential for illness by the manner in which they deal with the experiences of the bereaved for which the usual categories of cultural reality may be insufficient.

When a physician attends a person whose terminal illness has been long, complex or unusually dramatic, the relationship with the family may become particularly intense. The doctor, seen in the hospital regularly or visiting or calling the home frequently, becomes a temporary family member. For the about to be bereaved the physician may be seen as a particularly strong and emotionally giving individual at a time when the family members' emotions are in turmoil and they are more aware of their weaknesses than their strengths. Following the death, if the doctor merely "walks out," another loss has been sustained. It is important that some arrangement be made for follow-up with family members after the death. There are difficulties here, since the bereaved do not consider themselves ill. But despite the fact that such follow-up may require walking an emotional tightrope -- particularly when the doctor and the bereaved are of different gender and close in age -- it is an important service. It is obvious that physicians are rarely trained to deal with such issues.

Despite all the attentions given to the bereaved soon after the death, "Abnormal" grieving may not become manifest for many months, or even years -- and even then the tools for intervention are not clear. The one step that physicians, or any caregiver, can take that will be helpful, is to make the bereaved know, without question, that should they have need, the physician is there. Further, that the nature of the "need" is a personal matter and differs from individual to individual -- the bereaved should <u>not</u> feel it necessary to have to become sick in order to receive attention. Despite my obvious uncertainty about how intervention by physicians is best accomplished, it seems clear that the function will be facilitated if the doctor sets the stage for the follow-up at the time of the death.

Of all of the foregoing, ethics is as ignorant as science. Ethics has, however, one precept to guide behavior in the absence of systematic understanding -- respect for persons. Respects for persons and their wishes, fears, desires and concerns. Respect for persons leads inevitably to respect for families, whose relationships, loves, and conflicts existed long before the sickness and will continue long after the death -- when everybody else has left or lost interest.

The Community and the Nation.

The intense and persistent interest of the media testifies to the fact that the impact of the artificial heart implantation was not confined to Dr. Clark and his family. Only speculation is possible as to why the procedure is so important to the outside world. However, we are aware that the myths of our communities and nation about science, progress, nature, medical care, doctors, surgeons, researchers, courage, death, loss, tragedy and many other areas are built, supported or changed by events such as the artificial heart implantation. The question must be asked as to whether the research team should consider itself responsible in any way or in any magnitude for these more distant effects of its efforts. If the answer is yes, then considerable effort and money must be expended in research for which most medical teams are, to say the least, poorly prepared. If the answer is no, then what are the limits of responsibility in the development of radically different technologies? I am not arguing for an unlimited extension of responsibility but merely the recognition that placing a mechanical heart in an individual sick body is the beginning, not the end of the matter.

Conclusion.

The implantation of the artificial heart into Dr. Barney Clark, his subsequent illness, and his death are monuments to biology, human creativity, the dedication to others that marks medicine at its best, and the magnificence of the human spirit. The marvelous complexity of the body, sick persons and the world in which they live is not mirrored in the medical or ethical theory that guides the minds and hands of scientists and physicians. The case of Dr. Clark thrusts into prominence these failures of understanding: about how whole bodies integrate the functions of their parts; about what persons are and how they relate to disease in their bodies; about the relationship of persons to each other; about the impact of sickness on families; about the importance to communities of science, technology and their promise for the future. The artificial heart program gives promise that these areas of exploration will receive the attention they require so that in the future medicine will not only treat the sick, but understand them.