

An Inquiry about Clinical Death — Considering Spiritual Pain —

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Abstract

According to a paper published by the International Work Group on Death, Dying and Bereavement, “Each person has a spiritual dimension.” That means each person has spiritual energy and spiritual needs. In facing death, a patient suffers spiritual pain and needs spiritual care. This paper describes what spirituality and spiritual pain mean. It identifies nine types of fears and anxieties about death which become a source of spiritual pain: 1. Fear of pain; 2. Fear of loneliness; 3. Fear of unpleasant experiences; 4. Fear of becoming a burden to the family and to society; 5. Anxiety towards the unknown; 6. Fear of death resulting from fear of life; 7. Fear of death as a feeling that one’s life task is still incomplete; 8. Fear of death as fear of personal extinction; 9. Fear of death as fear of judgment and punishment after death. Five types of spiritual pain that seem to be frequent among patients facing death are discussed: 1. Loss of self-determination; 2. Loss of meaning; 3. Guilt feelings; 4. Loneliness and isolation; 5. Loss of hope. Three ways of preventing or reducing excessive fear of death and of lowering the various types of spiritual pain are suggested: 1. Death education; 2. Presence at the bedside; 3. Humor as an expression of love. (Keio J Med 58 (2) : 110–119, June 2009)

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Introduction

I have accompanied dying patients in my native country, Germany, in the United States and in my adopted country, Japan. There were numerous similarities in the types of spiritual pain experienced by patients in the three countries. Spiritual pain can be recognized by the questions the patients are asking, questions such as “Why me?” Dying patients in Germany and in the United States asked more questions expressing spiritual pain. Japanese patients seem to be more stoical, often refraining from asking questions of such a nature. Since spirituality and spiritual care are considered to be essential parts of terminal care in the West, this may explain the greater willingness of German and American patients to raise the issues of spiritual pain.

The reticence of Japanese patients is no proof that patients in this country do not experience spiritual pain. Offering more spiritual care in Japanese hospitals and

hospices would probably encourage patients to raise questions about their experience of spiritual pain.

The International Work Group on Death, Dying and Bereavement has published a paper “Assumptions and Principles of Spiritual Care.” There we find these important statements: “Each person has a spiritual dimension. In the total care of a person, his or her spiritual nature must be considered along with the mental, emotional, and physical dimensions... Facing a terminal illness, death and bereavement can be a stimulus for spiritual growth... Joy is a part of the human spirit. Humor is a haven needed even, or especially, in times of adversity or despair.”¹

In part one, I shall describe what spirituality and spiritual pain are. In the second part, I shall introduce nine types of fears and anxieties of death as sources of spiritual pain. Reducing a patient’s excessive fear or anxiety of death means reducing his or her spiritual pain. This is an essential part of spiritual care.

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In the third part, I shall discuss five types of spiritual pain that seem to be frequent among patients facing death. Through a multidisciplinary effort we can help a dying patient to diminish his spiritual pain. In the fourth part, I shall describe three methods of reducing spiritual pain.

What Are Spirituality and Spiritual Pain?

Spirituality is the human ability to be aware of ourselves, to think and reflect on ourselves, and to choose values. Furthermore, it is the capacity to search for meaning, to establish relationships with other human beings and with a transcendent being (often referred to as God).

Each person has a spiritual dimension and possesses spiritual energy. By searching for meaning, by deepening human relationships through love, and by establishing communication with a transcendent being, a person can experience spiritual well-being and can grow as a human being. Typical activities of spirituality are thinking, choosing values, searching for meaning, ethical reasoning, religious concerns, and humor as an expression of love.

Loss of meaning, decrease in the ability of self-determination, lack of human communication, and the feeling of being disconnected with a transcendent being can often result in spiritual pain.

Thanks to the hospice movement, there was developed a new interest in relieving the spiritual pain of dying patients. Spiritual pain is considered to be part of the total pain. Cecily Saunders, the foundress of St. Christopher's Hospice in London, has stated as one of the aims of hospice care that there be relief of "total pain," including the physical, psychological, social and spiritual pain.²

Spiritual well-being of a patient is usually characterized by experiences of meaningfulness, hope, connectedness, communication and inner harmony. If a patient experiences opposite emotions, he or she feels spiritual pain. Lack of self-determination, guilt feelings, meaninglessness, non-alignment, abandonment and loss of hope resulting in despair are typical causes of spiritual pain.

Excessive Fear and Anxiety of Death as the Cause of Spiritual Pain

A great number of patients confronting death suffer from an excessive fear or anxiety of death. This is frequently a major source of spiritual pain. By identifying which type of fear is prevalent in a patient, caregivers can try to reduce the excessive fear to a normal level.

I shall describe nine types of fear and anxiety that are frequent in patients confronting death.

Since the time of Kierkegaard, it has become common to distinguish between fear and anxiety. Fear refers to a

definite and specific object which is the cause of fear; for example, a snake, a disease or pain. Anxiety, in contrast, is indefinite, unspecified, a mood that is not directed toward any particular object. Applying these two terms to the confrontation with death, it would seem that both fear and anxiety are plaguing man. His fears refer to the pain of dying and saying goodbye to his beloved ones, to loneliness and loss of all his property as well as to many other concrete losses. But perhaps more painful than all these fears is the deep anxiety in the face of death. It is a general mood of anguish, doubt and uncertainty which has no clear and definite objective. Man feels himself threatened to the very core of his existence.

Fear and anxiety have a certain ambivalent character: they can be paralyzing and destructive if man allows himself to be dominated by them. But they can also be salutary and occasions for human growth if man confronts them in the proper way as a challenge.

Fear of pain

Fear of death is frequently a fear of pain. Dying is usually seen as a painful experience. I have seen many people die, and it is my impression that, indeed, numerous patients suffer much pain during the final agony. However, it is not only physical pain that dying patients fear. Besides physical pain there is the second pain, which often is stronger than the physical pain of the body, namely mental pain. Knowing that one has to die soon and has to leave behind all his or her loved ones and all possessions can create a terrible mental pain. Many patients also fear the third type of pain, social pain. This is often expressed in anxious concerns about the fate of one's family members and their lack of financial security.

For some, social pain means suffering from one's own helplessness vis-à-vis their family. A young father may suffer from the feeling that he cannot earn a salary any more and has become a mere burden to his family. Finally, there is the fourth pain, spiritual pain. Many patients suffer from a sense of meaninglessness of their life, from a feeling that they have achieved little and are now facing an early death and an uncertain future. Fear of pain often includes all the above four types of pain. Helping the patient to overcome these fears of pain means that one must help him to alleviate all four types of pain. Concentrating only on controlling physical pain is not sufficient to overcome the fear of pain. The hospice approach to pain control is always directed to the "total pain."

Fear of death as fear of loneliness

For many patients, the biggest source of fear is the fear that at the final stage of dying, they will be left alone. Fear of loneliness cannot be fully transcended for, indeed, man must in the last minute walk alone into the

dark night of death. However, we can greatly lessen the fear of the dying patient if we let him know that in the dying process he will not be left alone, that we shall be at his side till the very last moment.

Loneliness and isolation can take many different forms. In recent years, I have heard frequently from Japanese nurses that grown-ups would not visit their dying parents. Being busy with work seems to be the typical excuse. There is another loneliness when the patient cuts himself off from everyone except his immediate family. It is not rare that a patient does not want to see anybody, does not want to talk to anybody, or does not want anybody to see him sick. Caregivers have to respect the wishes of a patient. However, such self-imposed isolation may result in an excessive spiritual pain of loneliness. Caregivers must look out for a potential change of mind on the part of the patient.

Fear of unpleasant experiences

Many people have seen patients in hospitals who had lost their natural human beauty. Thus they are afraid that in the dying process they will present an ugly picture of themselves.

Lying in a bed is an embarrassing situation. Especially women often fear that without their usual make-up or their hair properly fixed they will look ugly. The whole atmosphere of the hospital room may be offensive to the eyes and noses of the visitors: untidy bedclothes, bedpans, medical machines connected to the body of the dying patient, the body odors, etc. A long and painful disease may disfigure the body of the patient; extreme pain may elicit negative emotions from the lips of the patient. Especially persons who have throughout life put great emphasis on a proper and dignified behavior and of presenting a pleasant image of themselves to the people around them will often fear that during the last period of their lives they will have to present an embarrassing negative self-image to their family and friends.

Fear of becoming a burden to the family or the society

Fear of becoming a burden to the family or the society is frequent, especially among elderly patients. It is a common source of spiritual pain. In Japanese culture, loyalty to the family and the society as well as the ethical ideal of not becoming a burden to others play important roles in the education and in the general thinking of the people. Therefore, it becomes especially painful for Japanese to feel useless and to be a burden for the time, emotions and financial resources of one's family. Many elderly ladies who visited temples where one prays for a sudden death (*pokkuridera*) answered to the question why they wanted to die a sudden death: "Because I do not want to become a burden to my family."

Since medical expenses are becoming more and more exorbitant, the fear of becoming a financial burden will probably become more acute in the future. Thus, it is of great importance to assure the patient that his family does not consider him a burden but will always see him as a highly valued member of the family. Such assurance is necessary to help the patient overcome this type of fear of death.

Anxiety of death as anxiety towards the unknown

Modern man is accustomed to acquire knowledge about all sorts of problems and thus to learn how to control the various situations he is confronting. However, death does not fit into this general pattern of controllable situations. Here, man is confronted with the unknown, being unable to control his/her new situation. Anxiety arises from the confrontation with the unknown and with being thrown into a passive role. This experience results into spiritual pain.

Fear of death resulting from fear of life

There exists a close parallel between fear of death and fear of life. Perhaps it is basically the same human emotion that at times is scared of life, at times scared of death. Or the same person may be afraid of life in his younger years and begin to fear death at a later stage of life. This close relationship of fear of life and fear of death may be an important key for analyzing the presence of excessive death fear. Profound fear of life may be an indication that the same person will probably suffer from an excessive fear of death when confronting an incurable disease. Early discovery of this problem can become an important help to assess and reduce the patient's fear of death.

Fear of death as a feeling that one's life task is still incomplete

Many dying patients are suffering from the painful feeling that their life task is incomplete. They compare the dreams of their youth with the actual achievements and feel a deep gap. Ending one's life without finishing one's life task or without realizing one's potential as a human person is a painful threat. Patients often become overly negative with regard to their past achievements; and tend to concentrate on the negative aspects, ignoring their real achievements. Fear of death means for such people primarily fear of not being able to achieve human as well as professional fulfillment.

People in the caring profession can help such people to overcome part of their exaggerated fears by pointing out the positive achievements and to help the patient discover a properly balanced view of his or her past life. It is

important to show the patient that the dying process itself is not merely a passive waiting for the end but can become an important process of human growth. The dying process itself offers a challenge and is a means for further self-actualization. If the patient discovers that an important part of his life task is still awaiting him by the way he responds to the challenge of dying, he will overcome the above mentioned fear of death and channel his precious energy into the positive task of achieving a final self-actualization in the process of dying.

Fear of death as fear of personal extinction

According to some psychologists, fear of personal extinction may be the most basic death fear. Self-preservation is one of the basic instincts of man; confronting death means confronting the possibility of losing oneself totally. As part of the self-preservation instinct, fear of self-annihilation is a natural reaction.

For people who embrace the hope for a life after death, deepening this hope can become a valuable way of transcending the fear of losing oneself in death. I have experienced frequently that such hope towards an eternal future is for some dying patients a way of overcoming this fear of death.

Fear of death as fear of judgment and punishment after death

For some patients, fear of death is primarily a fear of judgment and punishment after death. Throughout the history of mankind, there has been a nearly universal belief that man will be judged after death, that the good will be rewarded for their good deeds and bad will be punished for their sins. Buddhism, Islam, Christianity as well as several other religions express this fate after death as entering into eternal happiness of heaven or being punished in hell. A sense of justice leads many patients to believe that they deserve some punishment for the evil deeds they have committed. In caring for patients with such fears of punishment after death Christian spiritual caregivers often remind patients that God is not a God of judgment but a God of love who is ready to forgive any failures on the part of man.

Five Types of Spiritual Pain

Loss of self-determination as spiritual pain

The need to freely choose, the need for self-determination and for the control of one's own life is a basic need of man.

Throughout our life we highly value our right to freedom. Freedom is one of the greatest possessions of human beings. All around the world, people have become

very sensitive about depriving persons of their human rights. The right for self-determination has become a key word in our modern culture. Philosophically speaking, one of the main foundations of man's dignity and greatness lies in his capacity to freely choose.

Man's freedom and his capacity to control his life are severely threatened when he is hospitalized with an incurable disease. Lack of sufficient information or a paternalistic attitude on the side of a doctor may greatly curtail a patient's control of his life. The numerous discussions about informed consent and informed choice are dealing with this issue.

Efficiency in running a hospital or lack of time on the part of the staff may sometimes be the reason for curtailing a patient's freedom and for taking away some of the control of his life.

We must remind ourselves again and again that the need for freedom and for self-determination is one of the basic needs of a human person, also during the final stage of life. Loss of self-determination is a frequent source of spiritual pain.

The need for freedom includes also the need to be allowed to say goodbye and to die at the time the patient feels appropriate. Here I am not talking about euthanasia but about the permission family members and caregivers have to give to a patient to end the struggle for mere survival. I have seen patients who reached Kübler-Ross' fifth stage of acceptance or even what I like to call the sixth stage of expectation and hope for a new life beyond death, but where the family or caregivers remained on the stage of denial and would not give permission to the patient for ending the futile struggle. This not only creates pain for the patient, it also deprives him of his freedom to self-determination and of his human dignity.

At an early stage of a serious illness, patients usually try to preserve life at all costs. However, after a long and tiring battle against cancer, there comes a time when the patient has become exhausted. The body is weakened by drugs and various treatments. At some point the patient wants the permission to stop the futile struggle, the permission to die. Since some families are only thinking of prolonging the fighting, even if it is painful for the patient, nurses have here an important role of teaching the families when it is time to give permission to die. A nurse may then tell the patient: "You have fought bravely to live so long. You seem to be tired now. It's all right to stop fighting."

During our lifetime we often do things because we feel that our family or company or society at large expects it from us. Patients often feel that their family wants them to keep fighting for life even if they do not have the strength any more. For the family, to give permission to die can thus become the last act of respecting the dying patient's freedom.

Loss of meaning as spiritual pain

The loss of meaning is for many dying patients a major source of spiritual pain. Therefore, the search for meaning becomes an important task for overcoming this pain.

Our search for meaning can be divided into three different tasks: past, present and future. First we are looking to the past and search for meaning in our past life, in our achievements and failures. We try to make sense of what we have done so far. The second task is the search for meaning in our present experience: the meaning in our suffering, in our illness and in our facing death. The third task is directed towards the future: is there any meaning in our dying and is there a hope for an eternal future?

Our search for meaning is closely related to our value system. Many people will discover meaning in their past life knowing that they have achieved what they valued much. For some it may be the feeling that they have developed their human potential to the fullest; for some it may be the satisfaction of having raised a family; for some that they have done good things for their fellow human beings and have made this world a better place to live in. Scholarly, artistic or economic achievements may for some people become an important source of meaning. Loving one's fellow men and loving God are central for the meaning of life of most Christians.

The search for meaning in one's past life is a very individual and personal quest. What is the role of the caregiver in this search for meaning? The caregiver cannot create meaning for the dying patient, but he can help the patient to search for and find significance in past experiences. He also can become a sounding-board or a partner in the patient's difficult search for meaning in suffering and death.

Victor Frankl who went through the hell of the Auschwitz concentration camp discovered that precisely in extreme situations of suffering man's will for meaning is of extreme importance. Frankl developed a logotherapy; "logos" for Frankl signifies "meaning." Logotherapy focuses on the meaning of human existence, trying to assist the patient to find meaning in his life. Frankl is fond of quoting Nietzsche's words: "He who has a why to live for can bear with almost any how."

The second task of searching for meaning is concerned with the meaning of one's present suffering and illness. "Why did this happen to me?" "Why me?" are typical questions that express this quest for meaning. There is no easy answer to the question of suffering. Most patients do not expect so much an answer; what they are looking for is a person that can listen to them and who can show compassion. Cecily Saunders, the foundress of St. Christopher's Hospice in London who has accompanied thousands of dying patients often refers to the words of Jesus during his extreme suffering in the Garden of Gethse-

mane: "Watch with me." What he wanted most was that in the loneliness of his agony the apostles would be "with him."

Although there cannot be an easy answer or "solution" to the mystery of suffering and grave illness, there may be three levels on which a suffering patient may discover some meaning.

1) The expression or ventilation of his suffering in words can become a healthy, cathartic discharge of emotions. If a family member or caregiver listens seriously to the verbalization of the patient's suffering or even encourages the emotional release, the patient will experience that he is not alone in his suffering, and the solidarity of a careful listener will support him.

2) The second meaning may be found in the very process of searching for meaning. Even if no clear-cut answer can be found, the patient may experience the intellectual and emotional effort as such as meaningful.

3) The third meaning may be found in the growth process that a suffering patient goes through. We all have met people who have gone through great sufferings and have become more understanding, more compassionate and more loving through their painful experience.

Here we may also consider the classic example of a quest for meaning in suffering as portrayed in the book of Job in the Old Testament.

The search for meaning can express itself concretely in a shifting of values in life or as an adjusting of values. During our healthy years, values like professional success, achievements, social position, acquiring property and honor may have had high priorities. However, a patient suffering from an incurable disease cannot be satisfied by the same value priorities. In a shifting or adjusting of values, he may now put higher priority on relationship and communication. Since time is limited, time takes on a new dimension. The preciousness of time may become a high value on the priority list.

The third task in our search for meaning is directed towards the future: is there any meaning in our dying and is there a hope for a future after death? This is sometimes referred to as anticipating meaning. I have often experienced in Western hospitals and hospices that for patients with a religious background the hope in eternal life and the hope of reunion with their loved ones became a powerful source of emotional strength during the last days of their lives.

Some patients never thought about life after death during their healthy days. But they became intensely concerned about it when facing death. Some psychologists claim that self-preservation is the strongest human instinct. Therefore, it is quite natural that a person whose whole existence is threatened starts to think whether death means extinction and the end of everything or whether there may be a future life and a hope for reunion.

Families and caregivers should not impose their views on life after death but they should listen carefully to the patient and be sympathetic dialogue partners as the patient is struggling with the question of meaning and hope for the future. For some patients it may be helpful to learn about what various people, philosophies and religions have thought about this issue.

When we look back into history, we find numerous examples of people who faced extreme suffering or who faced death approaching at an early age and who answered this crisis with extremely heightened creativity. For me two of the most impressive examples are Mozart and Schubert. Mozart died at the age of 35; Schubert died before completing his 32nd year. Both were aware that their time was extremely limited. They discovered the preciousness of time and, during this limited time, lived extremely creative lives. They created some of the greatest music in the history of mankind.

Guilt feelings

The need to be forgiven or to forgive, the need for reconciliation arises from the experience of guilt feelings.

When patients review their lives, they often will remember persons against whom they have failed. Frequently, these persons will be members of their own family. Patients may also remember times when they have not lived up to their own ideals or moral standards. Smokers may feel guilty that they are themselves responsible for their lung cancer. Heavy drinkers may blame their uncontrolled consumption of alcohol as the cause of their incurable disease. No one is perfect. Therefore, various types of guilt feelings are quite common among dying patients. Guilt feelings do not only come from acts they have committed but may also originate from acts of omission; in other words, a person may feel guilty not for an evil deed he did but for some good deeds that he failed to do. Sins of omission may be the fact that he did not help a person who needed his help. Christians are all familiar with the norm for judgment in the Last Judgment described by Jesus in Mt. 25, 31-46. Those who do not enter heaven are not condemned for some evil they have committed but for the good they failed to do, for not helping those in need who needed their help. Guilt feelings are frequent sources of spiritual pain.

Several American surveys indicated that people whose image of God was that of a loving and forgiving God experienced a more peaceful death. For religious and non-religious patients alike the experience of being forgiven by their fellow human beings whom they had hurt, contributed greatly to a peaceful death. For some patients, the main task may not be to seek forgiveness but to forgive those who have hurt them and whom they may have refused so far to forgive.

Medical staff workers have often witnessed that a pa-

tient's unnecessary prolongation of the dying process was due to unresolved guilt or to bitterness or anger towards some family members. It seems that these deep-seated negative feelings trap a patient in his final agony and do not let him go peacefully into death. Refusal to forgive enslaves us to a painful negative past.

So far we have considered forgiveness primarily as a liberating and healing process for the dying patient. Forgiveness is also important for the surviving family members. When old wounds have been healed through forgiveness and reconciliation, the family members can enjoy more positive memories of the deceased person. These memories can become a significant help in the grieving process. On the other hand, if no reconciliation took place, family members will be burdened with negative memories and with regrets. This leads to a more complicated and painful grief process.

Loneliness and isolation

During man's whole life, the desire for communication is one of the basic human needs. This is even more true during the final stage of life. When medical science cannot heal a person any more, the patient's interest naturally turns from medicine to persons, from technology to communication. Loneliness and isolation are frequent sources of spiritual pain.

We often wear masks because we do not want to show our true face. There is usually a gap between the person we want to be and the person we really are. During the first stage of the dying process, medical professionals often hide behind masks of medical technique or behind the mask of vague phrases that conceal the truth. During the final stage of the dying process, patients usually take off their masks and reveal their true selves. Medical professionals and family members should do the same. This offers a new possibility of profound communication. If both sides open their hearts and truly listen to each other, the dying patient can experience a new – so far not experienced – communication. At the same time, caregivers should not see this as a one way communication. They also can learn and receive something new – something new about life and death.

During the past twenty years I have organized annual hospice tours for Japanese medical doctors and nurses. I had the opportunity to visit over two hundred hospices in a dozen different countries. In numerous hospices, I have admired the ways in which hospice patients supported each other in efforts to overcome loneliness and isolation. Many hospice patients come together regularly to share creative activities like painting, writing, making music, doing pottery or listening to each other's life stories. Such creative communication is a major help in avoiding or overcoming loneliness. It also can halt the process of social or cultural death that so often precedes

physical death.

Hopelessness as spiritual pain

One of the basic spiritual needs of the human heart is his need for hope. Hope gives man the joy of living and a positive outlook towards the future. Hope is the source of great spiritual energy in man. Although the object of hope lies in the future, hope itself is not in the future but is a sustaining energy here and now. The opposite of hope is despair. Hopelessness is a frequent source of spiritual pain. Despair is an extreme mental suffering here and now.

The greatest threat to hope comes to man when he is suffering from an incurable disease. How can man maintain hope if he is facing death? Usually hope is seen in this situation as hope for a cure. However, for many patients the object of hope changes. In other words, hope needs not to be seen only in terms of a cure.

In many patients, I have observed several stages of hope. Typical stages are as follows:

1) The first stage of hope is the hope that nothing is really wrong, that it is not a serious illness.

2) When it becomes clear that he is suffering from a serious illness, the patient will often move to the second stage, namely the hope that there will be a cure. Often, patients at this stage will hope for the discovery of a new drug or new treatment. For some patients, this hope will continue till the end.

3) Patients who have accepted the reality of their incurable cancer will frequently hope for more time. Some may hope to live till the wedding of a child or the birth of a grandchild. Others may hope to have time to finish a project or to travel once more to a favorite city.

4) When time runs out, most patients will hope to be pain-free till the end and not to be abandoned. The hope that somebody will be with them at the hour of death is an extremely important hope. Caregivers and family members should repeatedly tell the patient that they will not abandon him, that they will be at his side till the end. This helps to overcome the fear of loneliness and, at the same time, strengthens the hope of being with somebody at the hour of death. Several hospice doctors have told me that, in their first meeting with a new patient, they always tell them: "Today I will make you two promises: first that you will be pain-free and second that you will not be alone till the end."

5) Some patients move to the fifth stage of hope, a hope for eternal life and a hope for a reunion with loved ones. In German and American hospitals and hospices, I have seen numerous patients for whom, during the final hours, this hope became the most important spiritual support and consolation.

Caregivers and family members should not try to force this fifth type of hope on patients who do not embrace it

themselves. On the other hand, we should always be aware that, for some patients, this could be the most important hope. Our expressing unrealistic hope about recovery may offend such patients. It would not become a source of encouragement but of spiritual pain. I have witnessed cases where a patient had reached this fifth stage of hope and the family members talked only about stage two. This created a painful gap in their communication.

I have used the five-stage model above. Several patients whom I have accompanied during their dying process went through these stages consequently. But the process does not have to be in this sequence. Some patients may consider as their most important hope to remain pain-free or not to be left alone. Some may already at a rather early stage find their greatest spiritual support in hope towards an eternal future and a hope of a reunion with their previously deceased spouses. Each dying person is unique. But as caregivers, family members or friends, it can be helpful to know that the object of hope can change and that there can be stages of hope in the dying process.

I have often been asked after a lecture: "Is it really all right to tell a patient the truth about his incurable cancer, is it all right to deprive him of hope?" As it should be evident from the above description, truth-telling about an incurable cancer is not the same as depriving a patient of hope. On the contrary, if we do not tell a patient the truth, we leave him on the first stage of hope and deprive him of growing through the other stages of hope. In this situation, the patient clings desperately to an empty hope which will often, at a later time, turn into the opposite, namely despair. Thus, true information can be a valuable way of assisting a patient on his spiritual journey and of helping him to fulfill an important spiritual need, the need for hope in all its different forms.

Method of Reducing the Spiritual Pain of Terminal Patients

I shall present three ways of preventing or reducing excessive fear of death and of lowering the various types of spiritual pain of terminal patients: 1. Death education; 2. Presence at the bedside; 3. Humor as an expression of love.

Death education as a way of reducing spiritual pain

Since death has been treated as a taboo in recent times, many people have, throughout their life time, avoided any thinking about dying and death. When told that they suffer from an incurable disease, they are not prepared to confront their own dying and death. It is difficult to die a good death without any preparation. A lack of death education seems to be a major cause of spiritual pain of ter-

minal patients.

Throughout our life, we are facing various difficult tasks. Education prepares us to face these tasks in a mature way. The most difficult and painful task a human being has to confront is the process of dying and death itself. Whereas in other new situations we can always ask for the advice and assistance of other people who themselves had similar experiences, in the final hour of life, we are completely alone. No experienced guide can tell us what it is really like to die. Some doctors may pretend that they know what dying is, but their knowledge is technical and academic; nobody has a personal experience of the painful and lonely hours when the warm human life is gradually weakening and the cold shadows of death are approaching. No wonder that in the face of death feelings of utter helplessness, gradual separation from all possessions and from the people we love, as well as the uncertainty of the future after death arouse fear and anxiety in a dying patient. But this fear of death is by no means restricted to the final stage of life. Man is a thinking being, and throughout our life we cannot ignore the fact that one day we will have to die. As the philosopher Heidegger has put it, man is a “being unto death.”

From the above reflections, it should be evident that all humans need death education in order to confront in a mature way their own deaths. It would be irresponsible to neglect the preparation for death and, from the side of society, it would be cruel to have a terminal patient confront death without any preparation. For all other important tasks of life, society offers special education and preparation to people. It is, indeed, one of the most amazing facts that our highly developed educational system should have so completely ignored the task of educating and preparing people for life's most difficult days.

Death education should be offered at different stages of the life cycle. Mothers should use “teachable moments” offering information when children ask questions about dying and death. High schools and universities should offer systematic courses of death education. I know from my teaching experiences that university students show a great interest in dying and death. For thirty years, I have been teaching death education at Sophia University in Tokyo. An average of eight hundred students selected this course every year. Death education courses should be made available by culture centers or community colleges on a yearly basis. Numerous adults like to learn about death when losing a loved one or when facing cancer themselves. Since death education is at the same time life education, I recommend the study of death education for people who are confronted with a midlife crisis and for people who are facing retirement.

Presence at the bedside and nonverbal communication as ways of reducing spiritual pain

The second method of reducing spiritual pain is personal presence at the bedside of a patient. Feeling the presence of family members, friends or volunteers relieves the patient from the pain of isolation and loneliness. Active listening frees the patient from the fear of being abandoned.

Nonverbal communication may sometimes be expressed by a gentle touch. A caring touch often decreases the patient's anxiety and feelings of loneliness. If a patient offers a hand, handholding can enhance self-esteem and offer a sense of security and acceptance. Such nonverbal communication greatly reduces the spiritual pain of a dying patient.

Humor as a method of reducing spiritual pain

Visiting over two hundred hospices in a dozen different countries, I was repeatedly surprised to hear how highly humor is valued as an important element in the care for dying hospice patients. Many hospice doctors value humor as a way of lowering spiritual pain of patients.

One of the common misunderstandings about humor is that a sense of humor is a natural gift, the attribute of a born optimist or the reaction of a person favored by good luck. Often the opposite is true. Humor is not necessarily the expression of a cheerful character or of a natural optimist. A mature sense of humor frequently emerges from the experience of pain and suffering. Humor is not to be equated with cheap jokes or superficial merrymaking. Rather, a true sense of humor often reveals itself in times of suffering. If a person is going through a painful experience and can still smile in spite of everything, he has a genuine sense of humor.

Humor in its deepest sense is an expression of love. When we want to show love to a person, we first have to ask what this person expects and likes. Most people, especially the elderly, like a relaxed and warm atmosphere in daily life. Through smiles and laughter, we can create a pleasant atmosphere for our fellow humans. Every human being experiences hours of pain, darkness and loneliness, and is sometimes overwhelmed by the burdens of life. Humor is the magic that can change a tense atmosphere into a relaxed and cheerful one. Humor can thus become a healing balm, a medicine for the whole person. Smiles and laughter are the universal language of love understood by people throughout the world. Humor blossoms naturally in a heart that is filled with sympathy and love for other persons. Developing a sense of humor may be seen as an important aspect in the search for spirituality during the latter years of life. A warm smile and a sense of humor may sometimes be the most important

expressions of love.

For many or at least for some patients, a sense of humor can contribute greatly to make the final stage of life more meaningful, serene, and human. Of course, in a pluralistic society, dying patients reflect many values and have different needs. We in the caregiving professions are in constant danger of trying to generalize and categorize a patient, fitting every patient into the same mold, and pretending that we know best what every patient needs. A pluralistic approach refrains from forcing a generalized treatment upon the dying patient and attempts to be open to the individual psychological needs of each patient, encouraging him to live his final period of life in a personal manner and to die his own personal death in accordance with his own ideas and ideals. Not every patient has to go through Kübler-Ross' five stages of dying, and not every patient may find help and consolation in the prospect of immortality. But if a certain medicine is not therapeutic for all patients, there should be no reason to withhold it from those whose psychosomatic health may be improved by it.

It is within this framework of an individualized, pluralistic approach to the dying that humor and laughter may be a much-neglected yet important help to improve our quality of life. Our general culture tends to overemphasize the seriousness of life while grossly neglecting the importance of humor and laughter. There is no lack of superficial merrymaking, but that is frequently an attempt to escape from the boredom of the serious business of life. The shallowness of this posture becomes ever more evident as man's life approaches its end.

Humor is an expression and reflection of the infinite richness of joyful human life itself; it is a creative force of so many varieties that like life itself it eludes definition. Etymologically, the English word "humor" comes from the Latin "humor" (plural: humores). Medieval doctors referred to the "fluids" in the human body as "humores" that give life to man. For them, humores were not accidental but vital essences, the "juice and sap of life" whose flow gives vitality to a person and which, as a creative force, is constantly recharging human life.

Norman Cousins' "Anatomy of an Illness"³ advocates laughter as an important medical tool, as a powerful weapon in the war against disease. Cousins claims that through administering massive doses of laughter to himself he produced positive emotions and changes in his body chemistry that significantly contributed to his physical recovery. Ten minutes of genuine belly laughter had an anesthetic effect and gave him more than two hours of pain-free sleep. This laughter theory is based on scientific data showing that laughter enhances respiration and helps oxidize the blood.

Humor and laughter could become important answers or partial solutions to the following problems:

1) Death-fear – Fear-reducing humor

Fear of death is a common phenomenon among people approaching death. To a certain degree it is a healthy defense mechanism. However, too many people are burdened with excessive depressing fears. For them, a healthy dose of humor may be helpful as a fear-releasing therapy that will reduce their anxieties to a normal level.

2) Stress and tension – Humor and laughter as release of tension

Going through life-threatening illnesses, patients usually suffer from great stress and multiple tensions. To a certain degree, these emotions seem to be healthy coping mechanisms. However, constant stress and tension over an extended period of time can have a debilitating effect on the already weakened patient. Humor, laughter and joking can fulfill a tension-relieving function.

3) Aggression, anger and hostility – Humor and laughter as a cathartic reduction in the intensity of the aggressive feelings

Kübler-Ross describes anger as the second in the five-stage process of dying. Although I do not agree with the view that all patients go through a stage of anger, nevertheless, feelings of aggression, anger and hostility are quite frequent among people with a life-threatening disease. Encouraging the patient to develop a sense of humor and laughter could be for some a significant help in reducing hostile feelings.

4) Tendency to become passive – Humor and laughter as stimuli to activity and human growth

There is a natural tendency for the patient approaching death to become passive and to let the process of dying just happen. Our task in caregiving is to encourage the patient to search for a proper balance between the unavoidable passive posture and a personal acceptance of an active control over the last period of life. Humor and laughter can stimulate the active and creative forces of man. It is significant that Freud considered humor as the hallmark of maturity.

5) Isolation and loneliness of dying patients – Community-forming power of humor and laughter

Growing isolation and loneliness are for many patients the most painful experiences of the dying process. Not only do relatives generally visit less frequently as the patient approaches his final hours, but also several surveys indicate that even doctors and nurses decrease the number of visits when there is no hope of recovery. Thus, many patients are deprived of human companionship precisely at the time when they most need it.

The loneliness of the dying patient is a complex and multifaceted problem. Many patients may not even care about humor at this stage of life. However, numerous patients at this stage do appreciate humor and laughter as means of human communication and are greatly helped by them. Laughing together creates a feeling of solidarity and community. It may not be a remedy for all patients,

but for some dying persons, humor and laughter may be important ways of counteracting and overcoming the growing isolation and loneliness.

6) “Burned-out” cases among doctors and nurses dealing with dying patients – Humor and laughter as preventive medicine and therapy for the caregivers

Constant work with the dying may become a heavy emotional strain; the number of “burned-out” cases in the caregiving professions is relatively high. Evidently the people giving constant help to the dying need help themselves. Developing a sense of humor and laughter

may help them lessen the tension and create a more relaxed atmosphere.

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