

Death and Dying: Strategies for Improving Quality of Life of Terminally Ill Patients in India

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Abstract

How do people approach death and terminal illness? Why it is that better preparation of the loved ones and the young and those that will be left behind is rarely seen as a priority in certain cultures? This paper attempts to understand issues related to coping and the role of the social system and counseling in dealing with terminally ill patients. Based partly on a concept mapping study in a mid sized city it draws on the prevailing attitudes and meanings people have and the sense that they make out of early counseling to avoid too much grief. The paper identifies needs such as coping, a pronounced role of support systems, and developing strengths in the dying patient by sharing the right information about illness so that the patients are realistic. There is reason to believe that a terminally ill patient with sufficient knowledge about the condition assists himself/herself in self-coping and assists the supporters in better coping. There is very little by way of literature in this field in the Indian context and hence this study possibly would be a pioneer in documenting the strengths based coping mechanisms rooted in the culture and psyche of Indian people. Focusing on the strengths in Indian culture the researchers believe that it is possible to perceive dying as a process characterized by more dignity than mystery. Active grief and bereavement counseling, death education, training for effective healing, communication with family and health professionals to improve quality of dying with special focus on terminally ill patients is also highlighted in the Indian context. Finally, a humble attempt is made in this paper to recommend strengthening of hospice and palliative care in India.

Introduction

Two things that are certain in the world are the process of change or transformation and death. Death is an inevitable part of human existence. Since time immemorial, death has captured the imagination of poets, philosophers, artists, scientists, and lay persons alike, who have used the concept of death to understand and explain the meaning of life. Death and life are two inseparable companions, frequently in dispute, never very far apart as each depends upon the other (Feifel, 1977). Because death is a realm, an "undiscovered country from whose bourn no traveler returns" (William Shakespeare, *Hamlet*, Act 3, Scene 1), it is like a mystery which evokes feelings of fear, sadness and doom in us, when we hear or speak of death. It is not the fact of death, but the way we look at death which makes the great difference in coping with this reality. For many, failure to accept the ultimate reality of death may result in mental distress.

Each person's attitude toward death will affect nearly every activity of his or her life. If the attitudinal disposition is marked by a) fear of death to such an extent, that one becomes slave to one's emotions; b) suppression or ignoring of the thought of death by becoming engrossed in living, and; c) accepting death as a reality and preparing for it physically, emotionally, and spiritually. Accepting death as reality and being prepared for it requires deeper understanding of its various aspects, and in turn this would help in coping with this ultimate reality.

Issues relating to coping and the role of the social system and counseling in dealing with terminally ill patients, based on a concept mapping study in Vadodara city of Gujarat state in India forms the discussion in this paper. The researcher interviewed 40 adults from different walks of life - academics,

medical practitioners, entrepreneurs and managers, researchers, spiritual leaders, students from different streams, and lay persons. Perceptions, attitudes and meanings they gave to death and dying and terminal illness were viewed to identify needs such as coping and the possible role of supports for those who are dying and their family members that will be left. Respondent views on issues such as improvements to quality of life as well as preparing for the end of life were sought. There is very little by way of literature in this field in the Indian context and hence this study possibly would be a pioneer in documenting the strengths based coping mechanisms rooted in the culture and psyche of Indian people.

Views on death and dying

Death is an emotive issue; too sensitive and grave an issue that could not be talked about casually. This was amply evident in the reactions of the study participants, when they were asked to define death, their perceptions about good death and bad death. The question evoked reactions of sadness, awkward laughter, or caused the participants to pause for a while and introspect deeply before replying. Many of them became serious while describing their concept of death in their own words.

Physiological views of death

- Death was described by some of the participants as cessation of all critical functions of the body and functioning of vital organs and the ability to sense or feel.
- *When your brain and heart stop functioning.*
- *No breathing.*
- *When your nervous system does not respond..*
- *When slowly your body is getting damaged and you can observe that everything is going numb.*
- *When a person slips into a coma.*

Philosophical views of death

- Many participants were philosophical in their description of death. For them, death was “*the end of life*” or “*the end of physical being (existence)*”, and absence from the world - “*when one is no longer physically present (in the world)*”, which also meant the end of all hope, wishes and desires, and loss of that, one holds dear.
- *It is a stage of life when there is no hope for the future, nothing to look forward to.*
- *It is one’s inability to look beyond or wish for as it is the final stage of life.*
- *Death forces you to leave everything behind; it takes everything away from you.*
- Death is perceived as an inevitable, unwanted fact of life, as a “grey area”, an unknown dark area, which no one has previously experienced. It is perhaps this perception that evokes fear in people.

Spiritual views of death

In a spiritual sense, the meaning of death is merely separation of the body from the soul. The soul leaves the body for communion with the Divine. Death marks the beginning of a new life. In the words of a participant, a spiritual leader,

- *Death is akin to moving away from this materialistic world and your soul is meeting with God, the supreme authority. It is moving to a higher level. It is a beginning of new life. It is only end of physical entity of our physical being, when the soul leaves the body’.*
- *‘Death’ to some meant the end of merely the physical existence and the beginning of a new life. It is part of a continuous process. According to a participant, death is ‘not the end, but growth’.*
- *‘Death’ was also perceived as a great leveler that ‘visits everyone without discrimination of caste, class, or gender’.*
- *‘Death does not exist’.* A participant negated its existence and said, *‘Every moment since we took birth on this earth, we are inching towards death’.* According to two participants, a person may be

considered as good as dead, as soon as he or she loses zest for life, desire to live, and interest in all worldly matters, or if the person is outcast by the community.

Defining 'Good' death and 'Bad' death

According to the participants, a person may be considered as having died a good death, if there is *no physical pain or suffering, no physical diseases till one dies*. A good death is *painless filled with only happy memories*. If the person *has reached a certain age (70-80 years) and led a fulfilling life*, i.e. discharged all worldly responsibilities towards dependents and society, and has cultivated a sense of detachment from the world, has *severed emotional attachments and or involvement in worldly affairs or materials*, has a *cool and calm mental state*. Dying well also means *no dependence on other* including family members, community, and care takers in hospitals, and being *treated with dignity by family, relatives, doctors and nurses*. Good death is also *death with awareness and consciousness* such as death due to accident, cardiac arrest, etc. *as in such situations there is no prior knowledge* of its onset.

The ability to anticipate, predict or even determine the timing of one's own death, figures in Indian mythology and history. Death by self prediction and or determination was considered good death, because *one could die when one wishes to die*, and *death could occur according to one's wish*, and *pain, suffering and worries about the survivors* would have no place due to determinations and cultivation of *detachment*.

Similarly, according to the participants, a person may be considered as having died a bad death, if he or she *lived a very unsatisfied/dissatisfied life*. *Bad death was also perceived when individuals:*

- *had bad karma* (i.e., has done harm to society)
- *experience emotional pain and suffering*, and is *terrified of dying*
- *when persons feel helpless and incapacitated; suffer from painful diseases and are hospitalized and fully dependent on others*
- *are unable to cope with the idea of death or the process of dying*
- *suffer an undignified, dehumanized death*
- *suffer bad or ill-treatment (no dignity or honor) at the time of death at the hands of family or the hospital staff at the closing of life*
- *have no supports or care from the community; have to suffer insensitivity of care takers; and are constantly think about 'would happen to the loved ones?', after their death.*

Perceptions regarding Terminal illness

The word terminal illness is used for incurable diseases leading towards death. Lasagna (1970) considers 'terminal illness as a disease state whose presence rises in the mind of physician, patient or family an expectation of death as a direct consequence of the illness'. This indicates that in a physician's best judgment an identified trouble will cause death. At this stage the focus of doctors and patients changes from attempting to cure the illness or prolong life into trying to provide relief from pain and comfort for the sufferer.

Participants were asked to describe the characteristics of a terminally ill patient to understand how they perceive terminal illness. According to the participants, a terminally ill patient suffers a gradual weakening and cessation of all physical functions of the body, *terminally ill patient's body stop responding and it functions slowly, their bodies are weak, it's like break down of their whole nervous system*.

According to participants, terminal illness is difficult to accept and usually brings many painful reactions, from both the patients and their families. For a terminally ill patient, it is shocking to accept, that time is running out. For the family members and friends of the patients, caring for the patient is difficult, especially as they are aware that the person is *preparing for the final farewell*.

Participants felt that dying patients feel a strong sense of sadness as illness dominates their lives, and a number of positive and negative changes set in. They need sympathy along with empathy. They are highly worried about their progress towards death and start imagining problems of their dependents and other survivors after they are gone. They start ruminating on their life style, happy and sad moments, their mistakes and achievements throughout their life, and their behavior to and relationships with others; they start talking about rituals, norms and customs to be followed by their family members, after their death.

Participants also emphasized that the characteristics and reactions of terminally ill patients are dependant on variables such as age, level of maturity, attitude towards life and death, and personal achievements in life. These variables also determine the nature and extent of mental distress faced by the terminally ill.

Should terminally ill patients be informed about their condition?

Usually physicians do not disclose to their patients that they are terminally ill, they do not say that death is probable or inevitable in a particular disease, as there are several studies favoring the decision not to inform the patient. At times many patients themselves are not interested to know neither about recovery nor about occurrence of death, although the number of patients wanting to be fully ignorant about their progress towards dying is small. Glaser and Strauss (1965) believe that ideally the doctor must first confirm that whether the patients really want to know about their terminal stage and make judgments about disclosure of information. Half of the study participants opined that accidental death or sudden death as a good way to die. Hence quite a few participants felt that a person must not be told about his or her imminent death, so as to spare him the shock and pain of facing death, and worries about their survivors. The participants said:

- *'When one is enjoying life and suddenly come's to know that he or she has a fixed time left, that is a shock and such death with full awareness in advance is a very bad death'*
- *'When you are aware about the time left with you, it becomes very painful, shocking and unbearable'*
- *'When you are busy in your work and suddenly you die due to heart attack, you will not have to go through any psychological pain, survivors' tensions or any other dying related issues.'*

Some of the participants felt that regardless of whether or not terminally ill patients are formally informed about their condition, most of them become aware about their stage from the reactions and behavior of people around them. Those who advocated informing terminally ill persons about their condition reasoned that awareness of imminent death was important for a peaceful end, which is a good death. Consciousness about one's death was not only perceived to be important for preparing oneself for it, but necessary for accepting the reality of death, and in turn assisting a person to die peacefully and prepared.

- *Advance planning and preparation may be helpful in dying well if you are aware about your status of disease.*
- *When you are aware about it and prepare about it, than dying becomes more peaceful and easier.*
- *Information regarding remaining time period can be helpful for patients to get ready for the final farewell and assists with acceptance of the last phase of life.*

A wish to spend the remaining time in acts such as disposal of personal possessions, fulfilling wishes, seeking reconciliation for conflicts in their relationships, if any etc. surface as priorities. *'They must be informed so that they can workout property matters; deal with unfulfilled wishes as well as they may try to heal their wounds'*, a participant observed.

Some participants upheld the right of terminally ill persons to have information about their condition, as *everyone has the right to live and die according to their own wish*. One of the participants, a social science researcher, asserted that, *No one has right to decide the time of my death. I may be fighting with this battle. Still I need to be told, otherwise it is a betrayal.*

Several participants believed that a person's reaction to the information about his or her terminal illness and imminent death, was a completely subjective matter, and would depend on the mental make up and

circumstances of that person. Hence, they believed that information should be given, considering factors such as, degree of familiarity with the terminally ill person (*depends on how much you know the dying person*), *circumstances at the time of dying, mental state and consciousness of the patients towards their condition*. Information should be given in consultation with all stakeholders of the patients, *jointly by doctors, nurses, family members and care takers of the patients*. And most important, *the information must be forwarded very skillfully to the patient as well as to their family members, as patients are not mentally prepared for death; it becomes very difficult for them to cope up with this reality at the end of life*.

Notion of the last wish:

Participants were posed a hypothetical question – “If you came to know that you had very little time left in this world, what you would do? How would you like to spend the last days?” Once again, the spontaneous reaction to this question was a mix of emotions - initial shock, surprise, awkward laughter, speechlessness, and even avoidance of the subject. ‘*Oh, no*’, ‘*we have never thought of that*’, ‘*I just don’t know, it is too difficult and painful even to imagine*’, were some of the reactions that the question evoked.

However it was amply clear to many that, when faced with the prospect of death, they would take time out to fulfill their wishes, doing their favourite things that they were unable to give time due to their busy schedules or responsibilities. Other responses were spending time with their loved ones, doing something special and memorable for them, preparing their loved ones for their death, express their feelings, confess their love and mistakes they have made, confide or share secrets, seek forgiveness, say ‘good byes’ and thank all those who were significant people in their lives, were a bunch of other responses. This reflects their need for conciliation, cementing relationships with family, friends and relatives. There were also participants who said they would introspect on their lives, spend time in solitude. A few preferred a quiet exit without informing anyone of their death. Some said they would plan the disposal of their material possessions, property, and precious possessions, while a few declared they would give their possessions to charity. The responses of the participants also clearly showed their preoccupation with ensuring the welfare and well-being of their dependants and loved ones after their death, and their need to die peacefully, untroubled by worries, unfulfilled wishes or unresolved conflicts. The words of a housewife poignantly capture her concern for her family, who is completely dependent on her. The last thing she would do is to:

.....List out all the important things in the house and where they are kept....Then I will call all my children and teach them importance of our customs and traditions, our values and rituals. I will tell them to live with love and unity....take care of each other after I am gone.

The response varied according to the age, education and professional background of the participants. Those who were younger were keener on spending their last days in the pursuits of happiness, partying, undertaking fun-filled activities and spending all their earnings.

Coping with terminal illness and death

Participants were asked how terminally ill persons could be helped to cope with their condition and reduce their anxiety about dying. Acceptance of death was regarded as the first step towards dealing with death in a better way: *One must accept and remember that this is the ultimate fact of the life of any organism, that it is the universal law that whoever is born must die*. There was also a view that emphasised the need to see life as a transit journey, as illustrated by a participant:

‘We need to consider that we have come only on a visit to this planet Earth, and (that) we have to go back to our original home, which is in the universe. We need to be happy about this, just as we would feel happiness when we visit another city for a special work and return to our own city. Just as we would heave a sigh of relief, when we alight at the railway station of our own city, that yes, finally I am back home! -We must be ready to accept that one day- we also have to go back to our original home (the universe), from where we have come, and hence we must enjoy this trip, called life as much as possible’.

Another participant felt that death must be celebrated just as we celebrate life, i.e., birth. Thus acceptance of death would lead to change in one's attitude towards death, and make the process of dying more peaceful, easier, happier and painless, and less mysterious.

When asked about the possible roles that various sections of society (family and community, health care providers, psychologists and counselors, NGOs and social workers, academicians, corporate sector, government, etc.) could play in improving the quality of life of terminally ill persons, only a few respondents could think of any role for them. The roles they suggested were mostly for health care providers and family members in preparing persons for the end of life. In their view, health care providers could help terminally ill-patients prepare by informing them in a tactful manner about their condition, and treating them with dignity. *Doctors must not inform about patients' condition just by dropping the bombshell on the concerned person by directly saying, your mother is going to die*, said a participant. Family members and the community could help terminally ill patients accept their condition and reduce their anxiety by maintaining a cheerful countenance, by reassuring them that they would be able to handle bereavement well. As one of the participants, a health researcher, suggested, *upsetting facial expressions must be avoided while caring for the terminally ill patients, we must not walk around the patient with a long sad face which has a negative effect on the patient, the environment as well as the mood of every one around the patient.*

Acknowledging and accepting the patients' problems, sorrows, talking, sharing and listening to them, can also help in healing. A participant strongly recommended, *we need to focus on honest expression of our emotions for the patient. Sadness due to this separation is very painful. We must convey all these emotions to the patient and then start helping them to cope with the reality.*

Quality of life strategies

The participants perceived that the quality of life of terminally ill people is compromised by factors such as lack of control over one's own life, the seemingly long wait for death to occur, fear of dying, dissatisfaction with life in general, worries about the welfare of survivors, complete dependence on others on account of illness, ill-treatment or insensitive treatment by care takers (including family, health care providers, and community), the pain and humiliation experienced on account of this, and the feelings of complete worthlessness resulting thereof, and unfulfilled wishes and desires. All these factors contribute to elevating the anxiety level of the terminally ill-patients. Taking into account the prevailing perceptions and attitudes regarding death, dying and terminal illness the researchers suggest the following measures that would contribute to reduction of anxiety, better acceptance of death, and improve quality of life of terminally ill persons.

Training for healthcare providers

A review of the existing curriculum of medical colleges in India points to the gaps in sensitive patient and care giver handling procedures particularly in issues such as death, grief and bereavement. Medical students stand to benefit by increasing their emotional understanding of the patients. Such an approach would compliment their sense of objectivity in consideration of the disease, particularly as they are taught to be emotionally strong as deaths and impending psychological pain is a part of their daily routine. (Lasagna, 1970). Planned in service training in better communication and information strategies about terminal illness to patients and family members, for doctors already in practice would be very useful.

Informing terminally ill patients about their condition

On the basis of the response elicited from the participants and recommended practice relating patient information on their terminal status (Glaser and Strauss, 1965), the researchers feel that the decision to inform should be made by medical practitioners on a case by case basis, after due consideration of the terminally ill patients' situation. An assessment of the prevailing state of mind, strengths and attitude to accept the reality of death, and the capacity of individual patient to deal with the knowledge of their terminal disease, form the basis for making this informed decision, not withstanding its inherent conflict

with the rights of patient to information about their condition. For this, doctors would benefit by training. Such training may include clinical assessment skills and also skills to monitor, minimise the adverse effects that such information could have on the patient as well as their survivors.

Active grief and bereavement counseling for families and patients

Terminal illness has consequences for the patients, family members and other survivors intimately connected with the patient. The participants clearly indicated, that concern and anxiety that terminally ill patients have about their survivor, is an issue. In fact, a conclusive definition of good death from this study is the ability to prepare loved ones for one's death and learning to detach oneself so that one may die peacefully. Therefore it is important to involve the families of terminally ill persons, from the time of disclosure of terminal illness to preparing for the end. As one of the participant said *care with human touch by family members can be very helpful in healing the dying patient*. Few other participants said "Acknowledging, accepting and validating terminally ill patients' doubts and problems, by being with them, sharing one's own feelings and emotions, would also constitute a part of the bereavement process. Waiting for death at the terminal stage is a very painful experience for patients, especially as they have little control of their own lives. For counselors and therapists it is important to consider an in depth analysis of patient's thoughts, apprehensions, and anxieties, about their life, their achievements, and their personality before developing their counseling approaches.

Death education

To break the silence surrounding death, and to dispel fears, and to demystify death (from being perceived as something fearful or bad and to increase acceptance of death as a law of nature), death education could be introduced in schools, so that children may develop a right attitude towards death as adults.

Strengthening hospice and palliative care

A nation wide movement to develop more hospices as health care facilities is needed particularly in India, in order to provide a more meaningful palliative care. Palliative care aims to control distressing pain or symptoms, assist in treatment of terminally ill patients in more homely comfort and has potential to meet spiritual needs of the patients, in addition to providing bereavement counseling. Hospices, much like homes continue routine clinical nursing care and support services to terminally ill persons, apart from lending an atmosphere of pleasantness with gardens, flexible visiting hours, opportunities for fun with family members, relatives and friends of terminally ill and several diversion activities to engage patients in pursuing their hobbies, if they like. In palliative care, religious or cultural practices are respected as patients exercise choices to go and pray to their respective religious beliefs or to participate in important rituals preparing for death, like recitation of the Hindu scriptures of Bhagwad Geeta or scriptures or receive the sacrament from a Christian priest. Patients may be provided services such as transportation from hospital to their family homes, or if they chose to stay at their family home, medical help to enable patients to stay at home and offering bereavement counseling.

The concept of palliative care has not gained much popularity in India and it is still available for specific diseases like final stage of cancer attached to some large specialty hospitals in the country. Little is known about the type and quality of care provided by these hospitals in the absence of impact studies on their strengths and interventions. The researchers recommend that an intervention and outcomes research pilots to test the feasibility and sustainability of palliative care through hospices is needed.

Including spiritual discourse on death

India is a land of tradition of spiritual and faith healing. Its people irrespective of their religious persuasion have strong belief in prayer as a method of healing. This inclination can be positively geared particularly towards the end of life, through discourses from spiritual leaders. This would lead to greater acceptance death and coping with pain, living through suffering and loss and developing active detachment.

Helping the terminally ill patients in fulfilling their last wishes

Participant responses indicated that people begin to introspect when faced with the prospect of death. As said earlier in the discussion those who are dying have a need, among others, for conciliation, strengthening their ties with family, friends and relatives, resolving conflicts and planning disposal of their possessions. They look for reassurance that their dependents would be taken care of. Listening to their wishes and desires with empathy, and where possible and feasible, helping them to realise these wishes and desires, by communicating these to their family members, could be included as a therapeutic goal and as a strategy to improve their quality of life.

Conclusions

A veil of silence shrouds the discourse on death. A majority perception as a process marked by pain, suffering and fear, has taken many respondents to explore their philosophical inner core. As the concept mapping research illustrated the notions and meanings attached to good and bad death are important to the acceptance of death. 'Good deaths' make acceptance of the death easier, while 'bad deaths' make acceptance difficult, painful and even traumatic. Acceptance is also the key to coping with the knowledge of impending death and preparing oneself for its occurrence. The belief in past life or karma seems to make the acceptance of death easier. Sharing the right information about illness with the patients is very important so that patients are realistic and accept death. A terminally ill patient with sufficient knowledge about the condition assists himself/herself in self-coping and assists the survivors in better coping.

The researchers believe that it is possible to perceive dying as a process characterised by more dignity than mystery and improve the quality of life of terminally ill patients through training of health care providers in effective communication, active grief and bereavement counseling, death education, and strengthening of hospice and palliative care in India. Given the dearth of research in this area in India, there is a need for further studies also to account for cultural and regional differences in perceptions and attitudes towards death, among terminally ill patients. Additionally studies are needed on existing palliative interventions, in order to test, develop and run pilots that take note of the linguistic, cultural and regional diversity of India. And finally to develop strengths based perspectives of psycho social interventions the first step is to 'LISTEN' to what dying people have to say to enable them to cope better.

References:

Barney Glaser & Anselm Strauss (1965), *Awareness of dying*, Chicago: Aldine
Feifel, H,(Ed),(1997), *New meaning of death*, New York: McGraw-Hill
Lasanga,L (Ed) (1970).*The dying patient*. New York: Russell Sage Foundation.