

Death and Dying
Strategies for improving quality of
life of terminally ill patients in India

Ms.Nira Manghrani

Lecturer

Dr.Shagufa Kapadia

Associate Professor

Department of Human Development and Family Studies

Faculty of Home Science

The M.S.University of Baroda - Vadodara.

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.

Introduction

Death 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 makes the great difference in coping with this reality.

For many, failure to accept the ultimate reality of death may result in mental distress also.

Why this presentation in this conference!

Primary purpose in this research is to highlight how one can bring out the strength based coping among people with terminal illness and to understand how we may help jointly in improving quality of life of dying patients as:

- Health care professionals and Palliative care takers
- Academicians
- Government
- Family and relatives
- Ngo's and social workers
- Corporate
- Psychologists and counselors
- **Religious leaders and spiritual gurus**

Rationale of the study

This study draws on the ,

- perceptions,
- prevailing attitudes
- meanings people have regarding death and dying and terminal illness.
- To identify needs such as coping and the possible role of various sectors in supporting the dying people and their survivors in preparing for the end of life.

Rationale

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.

Methodology

- This presentation is based on a study which attempts to understand issues related to coping and the role of the social system and counseling in dealing with terminally ill patients.

It is based on a concept mapping study in a Vadodara city of Gujarat state in India, carried out through semi-structured interviews with 40 adults from different walks of life - academicians, medical practitioners, entrepreneurs and managers, researchers, spiritual leaders, students from different streams, and lay persons.

Perceptions about death and dying

➤ **Meaning of Death**

- Cessation of all critical functions of the body and vital organs and the inability to sense or feel.

Stopping of brain and heart functioning and “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

- The end of life. or The end of physical being (existence).
- Absence from the world - When no one is no longer physically present (in the world), which also meant the end of all hope, wishes and desires, and loss of all that one holds dear.
- It is a stage of life when there is no hope for the future, nothing to look forward.
- It is one's inability to look beyond or wish for as it is the final stage of life.

❖ Death was also perceived as a great leveler, which “visits everyone without any discrimination on the basis of caste, class, or gender”. “Death does not exist. 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”.

❖ “Death forces you to leave everything behind; it takes everything away from you.

Spiritual views of Death

- ❖ 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.
- ❖ *Death is like when you are going 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.*

What is “Good” Death?

- ❖ *No painful diseases plaguing the person.*
- ❖ *Painless death filled with only happy memories.*
- ❖ *If the person “has reached a certain age (70-80 years) and led a fulfilling life”,*
- ❖ *has cultivated a sense of detachment from the world.*
- ❖ *Having cool and calm mental state.*
- ❖ *No dependence on others.*
- ❖ *You die when you wish to die.*
- ❖ *When you are capable enough to prepare others for your farewell.*
- ❖ *When there are no grudges with any one. (Jab kisi se koi gila shikva na ho.) (Urdu)*

What is “Bad” Death?

When a person

- ❖ *has lived a very unsatisfied life.*
- ❖ *has done bad karma (i.e. has done harm to society).*
- ❖ *experiences emotional pain and suffering, and is terrified of dying.*
- ❖ *feels helpless and incapacitated.*
- ❖ *is suffering from painful diseases and is hospitalized and fully dependent on others.*
- ❖ *is unable to cope with the idea of death or the process of dying.*

- ❖ suffers from an “*undignified, dehumanized death,*
- ❖ *bad or ill-treatment (no dignity or honour) at the time of death*
- ❖ is constantly nagged by *worries about what would happen to the loved ones, after his or her death.*
- ❖ When your conflicts in relations are not yet resolved, your wounds are not healed and you die.

Awareness/Unawareness About One's Own Terminality

➤ Expressions favoring unawareness

- ❖ *“When you are enjoying your life and suddenly you come to know that you have a fixed limited time left with you, it is like a shock and such death with full awareness in advance is a very bad death in my opinion”.*
- ❖ *“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”.*

➤ Expressions favoring awareness

- *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, which is a good death.*
- *Everyone has the right to live and die according to their own wish.*
- *No one has right to decide the time of my death. I may fight with this battle. Still it has to be told, otherwise it is betrayal.*

- *They must be informed so that they can workout for property matters; other unfulfilled wishes can be expressed as well as they may try to heal their wounds.*
- It may help in preparing oneself for it by accepting the reality of death, which in turn would help a person die peacefully and well prepared.
- Patients can decide how they wish to spend the precious time they have left, for instance, disposal of their possessions, fulfilling wishes, seeking reconciliation for conflicts in their relationships, etc.

Terminal Illness and Patients' Characteristics

- *Their bodies are weak; it is like break down of their whole nervous system.*
- Terminal illness is difficult to accept and usually brings
 - many painful reactions, from both the patients and their families.
- It is just too shocking to accept, that there is very little time left. For the family members and friends of the patients,
 - caring for the patient is very difficult job, especially when
 - they know that the person is *preparing for the final*
 - *farewell.*
- Dying patients feel strong sadness.

Illness becomes an important part of their life.

- They need sympathy along with empathy.
- They are highly worried about their progress towards death
 - and start imagining the 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 life.
- They start talking about rituals, norms and customs to be
 - followed by their family members, after their death.
 -
- Waiting for death at the terminal stage is a very painful
 - experience for patients, especially as they have little control
 - of their own lives.

Strategies to Face this Challenge

Role of health care professionals

- Treating patients as “**human beings**” not as “**Objects**”,
 - must be included in the curriculum of Medicine.
- Need to be open and honest with patients’ condition,
 - type of disease, level of disease and possible solutions for recovery.
- Treatment methods being used and other possible
 - alternatives available for treating the same disease along
 - with expenses.

Communication with terminally ill patients

- Terminologies and words usually being used for
 - communication with terminally ill patients needs to be
 - used very carefully.
 - We must avoid loose use of such sensitive words .
 - Doctors must be very cautious before labeling someone as
 - a **terminally ill patient (Field, 1977).**
 - Health care professionals must be trained in communication
 - skills for passing the information to the patient or other
 - family members in a skillful manner.
- (*“Doctors must not inform about patients’ condition just by throwing away the bomb directly to the concerned person like, “your mother is going to die”.)*

•Nurses

- Needs to be expertise in handling such special patients,
 - they need to be sensitive enough towards the needs of
 - patients.
- They must try to understand the individual differences in the patients and need to develop different strategies for different type of patients during their treatment process.
- Nurses also can be helpful a lot to help the dying patient in improving social network at the last stage of life.
- Practitioners must strike a balance between care and cure during the practice. Hospital environment needs to be stimulating and not depressing .

Factors important to keep in mind before informing the patients for their terminality

- *Circumstances at the time of dying.*
- *Mental state and consciousness the patients have*
- *for their terminal condition.*
- Degree of familiarity with the terminally ill person.
- Proper prior assessment is important to know about patients' strengths and attitude to accept the reality of death.
- Final decision when and how to inform the patients must be left to the discretion of the doctors and family.

How to share information about terminality

- Information should be given in consultation with and with the involvement of all who are concerned with the patients.
- *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.*
- Training must be given to deal with the possibly adverse effects that such information could have on the patients as well as their survivors.
- Informers must be trained in grief and bereavement counseling.

Understanding different types of wishes people might have at the last stage of life

- ❖ *Will do something special and memorable for parents, prepare my loved ones for my death, express my feelings, confess my love and mistakes I have made, share secrets, seek forgiveness.*
- ❖ *Say 'good byes' and 'thanks' to all those who were significant people in my lives.*
- ❖ *Would introspect on my life, spend time in solitude.*
- ❖ *Will prefer a quiet exit without informing anyone of my death.*
- ❖ *Will plan the disposal of their material possessions,*
 - *property.*

Hospice/ Palliative care

- Palliative care aims to control any distressing pain or symptoms, to keep terminally ill patients comfortable, look after spiritual needs and facilitate them to be in contact with their family and friends.
- Palliative care also provides bereavement counseling. A hospice is a health care facility providing medical care and support services such as counseling to terminally ill persons.
- The atmosphere in a hospice is more like a home than a hospital, with less hospital routine, pleasant gardens and flexible visiting hours, so family members, relatives and friends of terminally ill

Current status in India

- Presently the concept of palliative care and hospices is not very popular in India. Palliative care is available in the country for specific diseases like final stage of cancer by a few large specialty hospitals in the country. Little is known about the type and quality of care provided by these hospitals.
- The researchers recommend that an intervention and outcomes research can be carried out on a pilot basis to test the feasibility and sustainability of providing palliative care and running a hospice. On the basis of the experiences of the pilot study, the intervention may be up-scaled.

Different activities for hospice centers

- Engaging patients in some creative work, their energy is diverted from illness for sometime and patients can pursue their hobbies.
- Drama, art therapy, music therapy , alternative healing methods also can be incorporated .
- Religious or cultural practices are also respected.
- Patients may be provided opportunities to go and pray to their respective gods, or to participate in important rituals preparing for death, like recitation of the Bhagwad Geeta (Geeta Paath) or scriptures (mantra jaap) by Hindus, receiving the sacrament in Christians, etc.

Role of Family, Relatives and Community

- ❖ *“Care with human touch by family members can be very helpful in healing the dying patient”.*
- ❖ “Acknowledging and accepting terminally ill patients’ doubts and problems, by being with them, sharing about your own feelings and emotions for them.
- ❖ The learning to detach oneself may be very difficult, but it may facilitate in peaceful departure from the world.
- ❖ Making the death of their loved ones as peaceful as possible.

Role of Academicians

- ❖ Introducing Death education in schools.

So that children may develop a positive attitude towards death as adults.

- ❖ Scientific researches can be an important proof for sensitizing the society for the need of high attention in the field.

- ❖ Given the dearth of research in this area in India, there is a need for further research to study the cultural and regional differences in perceptions and attitudes towards death,

Role of the psychologist and counselors

- ❖ Grief and bereavement counseling.
- ❖ In-depth analysis of patients' thoughts, apprehensions, and anxieties, how they have lived their life, their achievements, their personality type, their attitude towards death
- ❖ Counselors may focus on helping the patients overcome any guilt, fear and face any unresolved dilemmas.
- ❖ Effective training programs for health care professionals, general public as well as dying patients.

Role of Corporate Sector

Funding and effective management is a big challenge in any action research plan.

- ❖ Corporate sector can contribute in this area by investing money for hospice care institutes in India .

- ❖ Investing in long term projects in collaboration of health care professionals for continuous improvement for providing facilities for dying patients.

- ❖ Can help by donating amount to Hospice care centers and other Ngo's to get Income tax deduction .

Religious and spiritual leaders

- ❖ India is a spiritual country .
- ❖ where majority of blind followers of religious healers .

(For example, **Morari Bapu, Asharam Bapu, Osho, Ramdev Maharaj, Satya Sai Baba, Radha Swami, etc.**).
- ❖ Strong convincing power to change the attitude of mass.
- ❖ Time saving as well as cost effective strategy.
- ❖ This can be helpful in preparing children, family, society and nation for acceptance of death and hence better quality of living in present at the same time .

❖ These leaders/healers may incorporate ,

➤ Death perceptions,

➤ Sufferings of dying patient,

➤ Patients' psychological pain,

➤ Reactions and problems of family members.

➤ Coping strategies for peaceful end of life of dying patients .

❖ Patients with great belief in spirituality and religion can be greatly benefited from the sermons of their respective religious leaders. Their healing prayers, touch, “**Ashirvad**”, blessings or some times only meetings with patient also can be helpful. It will definitely have impact on the well being of the patients.

Social workers and NGOs

- ❖ Voluntary services to the hospitals and hospice care centers in different ways,
(for example arranging entertainment programs, alternative healing practices, art activities, drama and movie shows to alleviate the mood and divert patients' attention from their illness for some time).
- ❖ Organizing workshops, seminars, training programs and interactive sessions between doctors, psychologists and family members as well as for the general public can be very helpful for increasing sensitivity among Indian public for the same field.

Government

❖ Effective proposals based on scientific workable strategies to achieve the challenges in the field will be offered to the government, it may result in long term fruitful results. But it needs constant efforts with high sensitivity for human rights and importance of good facilities at the hour of dying. Later it may be considered seriously in policy making for India and fund allotment for the same.

❖ Governments also think for tax exemption for all the donations made towards the welfare of terminally ill patients or hospice care institutions.

Conclusion

Looking at the increasing number of terminally ill patients we all need to wake up before we die .

- ❖ Acceptance of this inevitable fact of life may have drastic impact on our current life style.
- ❖ There is high need to do interventional researches in the area specially in Indian context by understanding Indian religion .
- ❖ The most important is to "LISTEN" to what people want to enable them to cope from a strength perspective .



Thanks