

Coping with terminal illness: A spiritual perspective.

**Dr.Sanjeev Vasudevan, Professor & HOD, Dept. of Pain & Palliative Medicine,
AIMS,Kochi**

How does it feel to have an incurable illness and to know that you may die soon? Here I am, a seemingly healthy person, working hard to support my family and myself. One day I fall ill and my doctors tell me that my disease is incurable and that I am going to die soon. My whole world suddenly changes. I am faced with suffering and pain. The situations in my family also change. I am no longer the breadwinner. I become increasingly dependent on my family. What will happen to my family after I die? Who will look after them? I can't bear the pain of separation. Will they be able to bear the pain of loss?

And then there are other difficult questions troubling me. "What have I done to deserve this? Why did this happen to me? Why me? Why is God punishing me like this? What will happen after my death? Is there a life after death? Will I be punished for the sins I have committed voluntarily or involuntarily. What is the meaning of life? Is there a God or some other supreme power deciding our fate here and hereafter? Where do I find solace?"

These are some of the issues that confront a person who is facing death.

What can we do to comfort such a person? We can try to relieve their pain and physical symptoms. We can help them ventilate and perhaps resolve some of their emotional distress. We may help with their social, material and financial needs. But however much we do, we know that we cannot solve all their problems. Ultimately, how the patient copes with his / her condition depends on their inner spiritual strength. In this article I have tried to explore this least understood and least studied dimension of the person's personality.

In palliative care we try and find solutions for problems that can be solved. However, when a problem cannot be solved (and the fact of a person's impending death is one such problem for which we have no solution), the only way out is to learn to live with problem without being troubled by it. This is possible if the person's life isn't dominated by the problem anymore, if the person's mind has moved beyond the problem although the problem continues to exist. This capacity of mind to move beyond the problem – I have called it transcendence – helps the person find peace. This is what I would call spirituality.

Let us explore this in some detail.

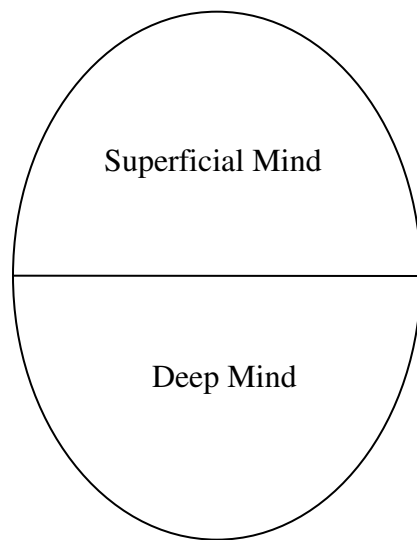
The joy of transcendence:

People suffering from spiritual pain can find peace by moving beyond their pain. The answer to spiritual pain lies in transcendence – transcending pain, transcending suffering and distress.

People with incurable conditions are faced with numerous physical, social, emotional and spiritual problems. Their minds may be so preoccupied with the problem that they are paralyzed. They see no way out. Life seems meaningless. However, it is possible for the mind to move beyond the problem so that the problem doesn't occupy their total consciousness anymore. This movement of the mind from a state in which it was so preoccupied with the problems it was facing, into a state where it is no more preoccupied with the problem, may be called transcendence. In other words transcendence can be described as a movement of the mind from the material plane, so full of pain and suffering, into a non-material plane. This non-material plane cannot be defined. It is a plane beyond the misery of pain and diseases.

Transcendence: A Model

In the works of Carl Jung we find this model, a division of the mind into two aspects viz. the superficial mind and the deep mind. The superficial mind is the mind which we use in our daily life – the part of the mind which senses, interacts and rationalizes. This is familiar territory (the material plane). The deep mind is the deeper part of ourselves, which is unaffected by the happenings in the world. It is that part of the mind which most of us have not explored. Transcendence can be understood in terms of the movement of the mind from its superficial (material) aspects to its deeper (non- material) aspect (Kearney1996).



When faced with an incurable disease, the superficial mind gets distressed. It analyses the situation, sees the enormity of the problem and reacts with panic and distress. It senses misery and suffering all around and sees no way out. Either through the practice of formal religious techniques or spontaneously (perhaps when the suffering simply becomes unbearable), the mind can move into its deeper plane. It then transcends misery and finds peace.

The movement of the mind from the familiar superficial aspects into that indefinable area called the deep can be defined as spirituality. Authors have described this experience- this movement of the mind as a shift in consciousness. In the Indian scriptures this process is described as “breaking the knot” (Mundako – Upanishad).

How can a person attain transcendence?

People reach this transcendence in different ways. There are many methods described in Indian scriptures. For ease of understanding, these are generally classified in to four:

1. Transcendence through action (**Karma Yoga**): Through the non-attached performance of ones duties.
2. Transcendence through devotion (**Bhakti Yoga**): Through the worship of a God with or without form. Worship can be purely mental or with the aid of prayers and rituals.
3. Transcendence through mediation (**Raja Yoga**): Through a process of mental detachment from the world outside.
4. Transcendence through philosophical enquiry (**Janana Yoga**): Through the study of the mystery of life.

This however is an artificial division. In practice people choose a technique or a combination of techniques to suit their temperament and natural inclination.

But not everyone needs to follow a formal technique to achieve this state of transcendence. Some can attain transcendence through the experience of suffering.

The story of K

K was a women in her late thirties with cancer When she came to us she had a large fungating, malodorous ulcer in the breast and was in severe pain. We taught the family to keep the wound clean. It took many weeks to control her pain and vomiting.

K knew her diagnosis and didn't expect to live long. She was very concerned about her two sons – 18 and 16 years of age. Both had a difficult relationship with their father and were dependent on her. The older boy was in trouble with the law and the younger son had dropped out of school.

Our social worker noted that K was overwhelmed by her problems and extremely anxious. The medical team felt that the emotional distress was making her physically symptoms difficult to control. Her pain and vomiting would worsen each time her son got into trouble.

As time went by K became bedridden, the ulcer increased in size and she developed severe oedema of the upper limb. She became totally dependent on others for her care. But though the ulcer and oedema had worsened, this longer distressed her. Her anxiety reduced and then the pain and vomiting could be controlled. She was also less worried about her children, even during difficult period when the older son had to stay away from home to escape police action.

During our last few visits she had no complaints although she had deteriorated physically and her social problems had not settled at all. She died almost a year after we first met her. Late one night she called her family to her bedside and told them that 'she was going'. She died a few minutes later.

K came to us in great physical and psychological distress. As her disease progressed her physical and social problems actually worsened. However as time went by she seemed to have accepted her condition and its inevitable consequences. The team members remarked on how much she had changed. Her carers told us that she was no longer worried about her situation although she remained conscious and mentally alert till the end. She was not depressed and was always hospitable to visitors. She seemed to have transcended her misery and found an inner peace.

K was a Hindu. But she was not a religious person and didn't use religious rituals to cope. She, like many other patients we have seen, seemed to have transcended her pain without recourse to any formal religious practice.

It is generally believed that people with religious beliefs cope better, when faced with a life threatening condition. However, this is not always the case in palliative care. We have seen many religious people who actually cope less well. There is no guarantee that a strong religious belief will help us in times of crisis. Believers may cling to God and religion in the cope of a cure (or for other material benefits) and when cure seems impossible they lose faith and became greatly distressed. They need to move beyond this dark despair, to find a greater strength to cope with the crises.

Religion and spirituality

Religion is not synonymous with spirituality. A person may not be religious, but he could be spiritual. And vice –versa, a person could be religious, but not spiritual. Spirituality could be considered as the goal of religion. Religion is the path, and spirituality is the goal. Spirituality is attained on transcending religion. As is mentioned in one of the Indian scriptures: "The Vedas belong to this plane-the material /plane. Transcend thou this plane ..."

There is also a passage from the works of the Buddha "The teaching is merely a vehicle to describe the truth. Don't mistake it for the truth itself .A finger pointing at the moon is not the moon.....the teaching is like a raft that carries you to the other shore. An intelligent person would not carry the raft around on his head after making it across to the other shoredo not get caught in the teaching. You must be able to let go".

We live in an age where great conflicts are taking place in the name of religion. It is important to recognize that the goal of all religions is the same, namely to help awaken the 'goodness' in man. Hindu, Christian, Muslim or Atheist, all can awaken the 'goodness' within them.

We can be too judgmental in our attitudes if we deny that the spiritual understanding reached by people who follow different paths is the same. Many of us believe that our own "way" is the only way. In this connection, I have heard about a palliative care worker who well meaningly placed a religious symbol beneath the pillow of a patient. The patient who was from a different religious tradition became greatly distressed and couldn't sleep at night, till a doctor removed the "offending object". What was a source of comfort to a palliative care worker was a cause of turmoil for the patient. As carers, we have a greater responsibility towards our patients.

A person who has realized the spiritual dimension – achieved transcendence – understands that different religions are different paths leading to the same goal. Mystics of all ages and creeds – Hindu mystics, Christian mystics, Sufis etc, have spoken the same language. All of them have broken out of their narrow confines of their religion and creed and expressed themselves in the universal language of spirituality. To such a person, everybody – Hindu, Christian, Muslim or an atheist – is the same. Everybody has the capacity to find the transcendent within them – to find the source of eternal peace and happiness.