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Health Care Needs of the Terminally Ill Cancer Patients

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Terminally ill patients have a special requirement with regard to their management. Some of the decisions that need to be taken pose dilemmas both for the patient's relatives and the treating physicians alike. They may also pose some pretty difficult ethical dilemmas for the treating physicians. Terminally ill cancer patients are a special group of patients who deserve a separate mention because of their special needs with regard to the health care. This group of patients may have open wounds which are often very foul smelling, they may have blocked intestines because of advanced growth in them, they may not be able to eat or drink anything because of blocked food pipe, they may be very breathless because of collection of fluid around the lung or they may be partially paralysed because of brain tumour. The scenario in each case is different and health care needs are also different. A question that may have to be faced in a lot of these situations is : How long should we continue the provision of health care needs in these situations? Or, to put it more squarely, should we hold back the provision of health care needs to these patients at any stage ?

SCENARIO OF A PATIENT

Working in a major government hospital, one encounters these situations often enough. I had a 65 years old patient with cancer of the prostate gland. Since the gland was causing partial obstruction to the urine flow, a part of the prostate gland was removed to restore the channel of urine flow by a procedure known as Trans-Urethral Resection of Prostate Gland. Radical removal of the gland was not possible because of the disease had already spread beyond the confines of the capsule of the gland. Patient was also given hormonal treatment to slow down the progression of the disease. Three years after his first visit, the patient developed severe backache. X-rays showed spread of the disease to the bones of the back (lumbar vertebrae, sacral bone and bony pelvis). For this, the operation of orchidectomy (removal of testes) was done to cut out the supply of testosterone to the tumour because this tumour thrives and progresses rapidly on testosterone. Patient had relief of pain for a period of about 6 months. When the pain recurred, the patient was put on analgesics. Over the space of a few months, the patient began to require injections of pain killers, initially once a day but later more often. The pain relief became increasingly more difficult. Patient was hospitalised for pain relief where he remained for about 18 months before his death. During the last nine months of his life the patient was completely confined to bed and was nursed in bed. One day when I walked in for a morning round, the patient said "Doctor why are you keeping me alive - why not give me an injection and relieve me of the misery forever". I sat down with patient and had a long talk to reassure him and give him some hope. From then on his plea of this nature became a constant feature. The patient was suffering severe pain and there was very little we could do to effectively relieve his pain. Later the disease spread to the ribs which only added to his pain. I can remember the face of his man vividly even now and his typical manner of speaking every time I went round to see him. I knew there was no hope of recovery for him and so did his relatives, particularly his son. "Why are you keeping me alive ?" he would say every time with a painful expression on his very emaciated face. And I know that last nine months of his life must have been a sheer hell for him. During the last few months of his life, patient was crouched in foetal position all the time. The disease spread to the bones of his skull near the end and he was not able to feed himself. We resorted to Ryle's Tube feeding during the last two months or so of his life. Patient developed a severe chest infection near the end which did not respond to the antibiotics. At the time of his death,

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this patient had also developed a few bedsores. Nursing care posed special problems during the last few months of his life and imposed a tremendous strain on the nursing services of the ward where this patient was kept. About a month before this patient's death, his son talked to me and asked me whether it was worthwhile to keep his father alive in that state when he was suffering so much. During the past months and years I had an excellent rapport with this patient's son. The son was caring and looked after his father extremely well. It must have taken some courage for the son to come up to me and ask me the question that he had asked. I have no doubt that this question must have been in his mind for quite some time before he actually talked to me. I empathised with the son by having a long talk with him seperately and also told him of the ethical and legal situation in this context.

SCENARIO OF A SECOND PATIENT

A fifty year old lady came to me with cancer of the right breast about seven years ago. After confirmation of the diagnosis I did the operation of Mastectomy (removal of the breast) on her. Since there was spread of the disease beyond the breast and into the lymph nodes of the axilla (arm pit), patient was given radio-therapy and chemo-therapy. Patient was free from the disease for a period of about four years. However, during this time she had developed swelling of the entire right arm (lymphoedema) because of the removal of the lymph nodes from the right axilla at the time of the initial surgery. Four years after the surgery patient came back with recurrence of the disease in the axilla and the adjacent part of the arm. The entire area was surgically removed and a small dose of radio-therapy was given again to the axilla. The operation of bilateral oophorectomy (removal of the ovaries) was also performed in order to cut off the supply of oestrogen hormone to the tumour which is known to thrive on oestrogen. One year after the second operation the patient came back with yet another recurrence in the axilla. This time only chemo-therapy could be given to the patient as we had exhausted all the other modes of treatment. There was no response to chemo-therapy and the tumour went on increasing in size and ultimately ulcerated. During this time the swelling of the entire right arm had also increased. The diameter of the right arm was about five time the diameter of the normal left arm in this patient. We could see the condition of the patient becoming worse and yet there was nothing effective that we could do to treat this patient. Since the area of recurrent growth involved the arm pit (axilla) and the adjacent part of the righ arm, we debated the option of amputation of the right arm thereby taking away the entire growth with it. After several interviews withe the patient and the close relatives, the patient finally gave her consent for the surgery to amputate the right arm. Amputation itself was done nearly two years after the second operation (six years after the first operation). Patient made an uneventful recovery from this operation but six months after the surgery she was found to have spread of this disease to the lungs. She also had collection of fluid around the right lung (malignant pleural effusion). In a matter of few days, the patient became breathless because the disease was spreading in the lungs. We removed the fluid around the right lung which gave her some relief but the fluid came back within a matter of one week. The patient was not able to lie down and had to sit bent forward in order to get some breath. She would even sleep in this position. This state of shortness of breath continued for many days. The patient was hospitalised about two months before her death. Initially, the patient would plead with us to give her the medicine which would relieve her breathing problem. But later on, she only wanted to be given some medicine by which her life would end. We all watched helplessly while this patient gradually became from bad to worse. I had several rounds of discussion with the relatives who also were of the view that this state of extreme distress to the patient be relieved by giving her a heavy dose of any medicine (including morphine about which they knew). While I shared their grief and anguish over the state of extreme distress to this patient, I had to tell the relatives that ethically and legally for me their suggestions were unthinkable to carry out. The patient finally died two months after her last admission.

DISCUSSION

The author has the experience of looking after a large number of terminally ill cancer patients with a full spectrum of involvement of different organs of the body and the special problem that each patient faces before death. Two of the secenarios have been described above. The description of each of these situations would make a book better than any fiction material that one has read on the subject. Each of these patients go through a real life drama

which is more intense and more intricate than the known fiction material that exists on the subject.

The common thing in all these patients is that their suffering at the terminal stages of illness is very intense. The distress of the relatives of the patients is also very intense. It is very hard for the relatives of a terminally ill cancer patient to see their close relative suffer in this manner. For patients with malignant ulcers on the body which fungate and emit foul smell because of bacterial infection, their situation is even worse. The relatives of most of these patients would like these patients to be cared for in a hospital or a hospice because they may not want to see their relatives suffer but also it is humanly intolerable for such a patient to live within the family because of the foul smell. It is therefore natural for the patients suffering from terminal cancer and their relatives to think of relief from this situation by way of hastening the terminal event. For the caring relatives (like the son the patient with cancer of the prostate gland) the agony of seeing their close relative suffer endlessly with pain (or with extreme shortness of breath as in the second case) is too intense and too prolonged. It is natural that one is not able to see the suffering of a close relative for too long, particularly if the relief from the suffering is not there.

In the western world terms like "death with dignity" are used to describe a state where a patient suffering from terminal illness and being totally helpless wishes for the life to end rather than continued prolongation of the suffering with no end in sight. And, the wish for a dignified end to life does deserve a consideration. Perhaps we in India are not very expressive to describe our state of mind openly. Deep down, perhaps, we also want a dignified end to life in these situations but are not able to say so for whatever reasons.

CONCLUSION

In the light of what has been described above, it is perhaps appropriate that there should be a debate on the question of passive euthanasia in some of these situations. The discussion should include the religious leaders, the expert in law, people from the medical profession who have a personal experience of dealing with these situations and, of course, the relatives of some of the patients who have died in the type of situations as described above. In my personal view I strongly feel that there is a justification in enacting a law to deal with these special situations. The law should be stringent enough to prevent any misuse by any party. Of course, this is for the legal profession to consider and advice on. For the moment, the Hippocrates' Oath, the ethical considerations and the legal requirements require the medical profession to continue to care for these patients in the best possible manner till the very end. One has practiced these high standards of care in these situations till the end without any exceptions. But now perhaps there is a need for a fresh look at these situations. It will be relevant to mention that very recently the US Supreme Court ordered the removal of a feeding tube that was keeping a patient with the name of Edna M. Folz alive. The patient Ms. Folz who was suffering from advanced Alzheimer's disease, died 18 days after the removal of the feeding tube (reported on page 7 of the newspaper The Pioneer dated 18th November, 1997).

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Surrogate Motherhood-Legal and Social Issues

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ABSTRACT

Motherhood is a relation of blood and emotions born out of carrying a foetus and it can never be perceived when the baby is grown in a rented womb. Surrogate motherhood is a newer development in the management of infertility. It assists infertile couple to procreate by different techniques. The advantage is that a woman without a uterus but with functioning ovaries may have her child with the help of a surrogate mother. The surrogacy as a concept is not new. We find references in the Bible, as also in the Mahabharta & Ramayana. The concept is old but issues are new and amplitude is wider.

2. No doubt assisted reproduction is a great scientific achievement, it raises many emotional, social, legal & ethical issues which are faced by the couple, the surrogate mother, the child, the society, the donor as also by the doctor.
3. In many western countries surrogacy is an accepted mode of having a child. In the U.K., it was legalised in 1990 for infertile couples, whereas in the USA surrogacy arrangement even on commercial basis is also allowed. In India, on the other hand, because of high priority given to morality & ortho-dox societal set-up, the practice of surrogacy and related issues have wider ramifications. In some cases the situation takes an ugly turn bringing law enforcing agencies and the judiciary to play a remedial role.
4. And now cloning opened a pandora's box.Its application in human beings is a challenging ethical issue confronting the society. Only time will tell whether this asexually applied sexual method will be accepted for reproduction or not.

DRUG DEPENDENCE : ADOLSCENTS' PARADISE; NATION'S DOOM.

ABSRACT OF PAPER TO BE PRESENTED AT INTERNATIONAL CONFERENCE ON GLOBAL HEALTH LAW

Providing healthy living and promoting good health to every citizen, should be the primary concern of every nation, be it developed, developing or underdeveloped. This goal is achieved by generating awareness among the masses as also through legislation.

A malady which has affected almost every nation in the world in recent times, is the menace of drug abuse, tobacco consumption ans alcoholism. Although, there are certain legal measures which are helpful in curbing the abuse of drugs like opium, morphine, heroin, pethedine etc., the serveillance forms, more effective an approach to deal with the national health problem. The related vital issue of adolescent drug dependence, (enumerating various drugs which are abused by the youth), their harmful effects, and remedial measures are important areas of discussion.

National Surveys conducted from time to time have indicated that more and more adolescent school and college youths are falling prey to drug abuse, consumption of alcoholic beverages and cigarette smoking. Initial experimentation, periodic recreation and compulsive chronic pattern are the three stages of adolscent addiction. Peer pressure, alienation, hedonism, mass

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media advertising, affluence and boredom are the most frequently cited factors leading to spread of drug abuse.

The substances which form most common of abused items are heorin (brown sugar), barbeturates, non-barbeturates sedatives like chloral hydrates, mandrex, anti-anxiety agents such as Chlor-diaze pride, diazapam; stimulants such as emphetamines, Cocaine and certain psychotomimetics like LSD. Tobacco is consumed in the form of cigarette smoking and chewing by mouth, which accounts for approximately one third of all cancer deaths. Alcohol consumption which has increased in recent times due to changes in socio-economic conditions, often results in drug tolerance and physical dependence. Alcoholism which causes not only debilitating pathological conditions such as chronic hepatitis, may also lead to tratogenesis in women.

Existing laws and enforcement machinery needs a relook in the changed scenario emerging from tremorising effect of western culture and civilization of the Indian youth.

The remedial measures are the effective implementation and enforcement of existing laws, making them more potent and effective, empowerment of enforcement agencies, formulation of new laws to ban drug use, publiactive and passive smoking, as also imposition of ban or providing for regulations or drinking alcohol in public functions (as has been done recently by Delhi Administration). There is need of general public awareness and publicity among the masses (towards health hazards caused by the drugs, tobacco and alcohol) through mass media-print and electronics.

The Governmental and non-Governmental Organisations as also Voluntary social agencies need to come forward to pursue this cause of societal good to avoid Nation's doom.