

THE STORY SO FAR

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A few years ago, I was asked by a friend as to how I came to be working in Palliative Care. At that time, Palliative Care (PC) used to be synonymous with terminal cancer care. In all innocence, I replied that cancer fascinates me. She was shocked and horrified to hear this. Moving a relative afflicted with cancer, she had enough by way of experience of walking the length and breadth of cancer institutes, seeing the disease ravage young or old, rich or poor, with all its ramifications. 'Fascinate' was not a word to be used with cancer, as far as my friend was concerned.

Besides her very humanistic experiences, my limited cancer experience of seeing cancer cells in the laboratory paled in comparison. In the laboratory, growing under controlled conditions, the way a cancer cell behaves is vastly different from how a normal cell behaves and that is fascinating. But this aspect, when transplanted into a living human being evokes fear, revulsion, pity, sympathy and whole gamut of emotions in a layman. Some would not even think of offering support to cancer patient. Many are people who have asked me whether I don't feel depressed seeing so much suffering, I do n't, nor have I heard anybody in this field complain about being depressed. Perhaps because we feel there 's so much to be done for the patients. After getting trained as a volunteer, the outlook towards the patient is positive. There is always something that can be done to improve the situation a patient faces which is what PC is all about.

This is one reason why we decided to bring out a regular, news letter. To educate the public about palliative care, to inform our well wishers about the activities of our society and in between, to include some general articles on cancer and treatment methods.

Nowadays PC has come to encompass all chronically ill and bedridden patients. People with Peripheral Vascular Diseases (PVD) arising out of smoking, Paraplegic patients due to a fall or accident, patients with kidney disorders, patients with mental ill health, infact anybody who is chronically ill and/ or bedridden, unable to take part in normal human activities. For such patients, what a conventional doctor / sister can do is very limited, it is upto the general society and people encompassing it to lessen their distress and suffering. To this end, I have tried

to include in the editorials in Reaching Out issues some points to think about.

Choosing one's attitude in any given set of circumstances the pride of place. According to Viktor Frankl's Logo therapy, choosing one's attitude is the last of freedoms available to man which nobody can take away. And in any given situation, choosing to remain positive helps to face the situation tremendously.

Christine Clifford and her cancer club comes next. Christine Clifford is a cancer survivor and a few days into knowledge about her cancer she 'discovered' the power of laughter. The mental picture was so powerful, she has written whole books on the subject complete with cartoons for better effect. One such book is 'Cancer Has its Privilege: Stories of Hope and Laughter' written by Christine. Read on and you will discover that laughter is not only the best medicine, it is the sunny side of existence. But it is important that it is the patient who has to admit that timing is right for laughter to be admitted into his/her life.

The Staine's story that hit headlines gave another piece to be included in the editorial. By forgiving her family's killers so unreservedly Gladys Staines has demonstrated the power of healing under the act of forgiveness not only to our enemies, but also to ourselves. So many of our patients have an underlying anger in them - why me ? attitude. Where we are directly responsible for our condition or not, it is essential that we first and foremost forgive ourselves and allow healing to take place.

If we can talk to others about our anger, our negative feelings, that can also help. Towards this end, patient forums serve to bring a feeling of closeness. Such a patient forum was organized in 2004, bringing in people from all walks of life, for a day, to be spent in the company of our patients and a close relative. For many of the patients, it was a first time experience to share their thoughts and voice their concerns. It certainly was an emotionally charged day.

What most patients want is to have their pain relieved, avoid being a burden to their family and maintain a sense of control and dignity. The answer for this seems to lie in hospice care. Hospice meant for terminally ill patients living in a home which has all facilities for their care. In situations where a cure is no longer possible., a change in focus to giving them maximum

possible comfort is needed. Hospices fulfill this criteria. To acknowledge the role of hospices and PC Day generally falls on Oct. 8. individual PC units can arrange programs either as awareness drive for fund raising on this day. What is special about this occasion is that PC volunteers the world over are unified on this day.

The Road Ahead

With PC now encompassing all clinically ill patients, it is natural that a shift in focus from cancer is required. Problems faced by bedridden will be stressed, so also possible solutions. The identity crisis faced by the so disabled when they are suddenly faced with inability to work is a case in point. Who we are and what we do are two very different things, but very often, these two overlap and what we do, often identifies totally with our being. And when suddenly faced with a debilitating illness, plus the loss of job leading to financial insecurity, the patient often gropes in the dark, as to who they are, in essence. It will take a while to be on firm ground.

Spiritual care in a journey that involves helping people to come to terms with the fact that their life will end sooner, than later. We should explore with the patients what they want and need and allow the patients “to be”. There is also scope to help the patients identify their own coping mechanism and direct care to support them.

Those people who are denied physical intimacy and tenderness due to mutilating surgery and chronic disease are extremely vulnerable to depression. Likewise the partner of the patient might need support and help to explore new ways of expressing love and affection. Patients who are seriously ill have depleted energy reserves. The normal tasks of eating, grooming and excreting become onerous and difficult. However, research has shown that

patients do enjoy being hugged and cuddled, even when seriously ill or dying. We owe it to the dying to enable them to make the best of the life that is left and to the partners who will soon be bereaved, we owe the opportunity for cherished memories.

Society’s attitude towards death may have a significant influence on bereavement outcome. So long as death is seen as a totally negative experience, to be avoided at all costs and pushed into the background, the process of grief will be seen as something to fear and avoid. If death can have a more central place, perhaps, the process of grief can be better understood and accepted. This would allow the bereaved to have some time and space to move at their own pace and in their own way through their grief.

Quality doesn’t happen by accident. There needs to be careful planning to ensure consistent quality in PC. For this, both research and audit is essential. There are six dimensions to illuminate quality in health care.

Appropriateness: that the service is what the population needs.

Accessibility: that the services are accessible.

Effectiveness: that the service is achieving the intended benefit for both the individual and population.

Acceptability: that the services are provided such as to satisfy the reasonable expectations of patients.

Efficiency: that resources are not wasted on one service to the detriment of another.

Equity: that there is a fair share for the population.

Research is concerned with covering the right thing to do; audit with ensuring that it is done right. Research is aimed at primarily concerned with improving standards of care. Audit and research are interdependent.

