Nursing Care of the Terminally Ill Cancer Patients

Sr. Herta Mempra

Nursing is an art of loving and serving with nobility, unselfishness and efficiency, the sick and the helpless. Nursing calls for an extraordinary degree of dedication, sincerity and commitment. Sensitivity to the sufferings of others and a powerful determination to comfort and care are the hallmarks of the nursing profession. No doubt, doctors and nurses form an inseparable unit of the medical team from whom we expect professional skill, reassurance and confidence. But nurses are expected to give a little more, and that is personalised care and loving attention. In the process of alleviating the pain and agony of the diseased or injured, in providing relief to the sick and suffering, a nurse becomes a sort of foster mother to every one in his or her sufferings and it is the heart of the mother or sister that automatically goes out to the sufferer. Thus the nursing profession is one of "Serving and Giving". No hospital is complete without the compelling presence of the "Angel in White" who takes care of the patients and helps the process of recovery. A nurse stirs up trust, confidence and hope in the corridors of the hospital wards.

Nursing the terminally ill cancer patients is a demanding service, as the advanced cancer patient requires continued care to alleviate the many distressing symptoms of failing health and progress of the disease. In the terminal stage of the disease, it is important to remember that one should forget the disease and concentrate on the patient to relieve his pain and distressing symptoms. It is still an astonishingly common misconception that all patients with cancer die in terrible pain. Often indeed we probably spend more time with patients whose symptoms are intractable than those cases where symptom control proves straightforward. Whilst this is probably an over-protective compensation for our helplessness, we may unwittingly be providing the form of support they most value. To care means that we accept the patient and family and deal with the issues and concerns that are important to them. It is desirable and advantageous that every patient has an individualised care plan which identifies needs, problems, action taken, and outcomes. This plan should be regularly evaluated and updated. Nothing is held back, everything which will improve the patient's quality of life is given with love and understanding rather than taking an attitude that nothing more can be done for these patients. The attitude here is to make the patient's end as useful, comfortable, enjoyable and dignified as possible.

The care of the terminally ill cancer patient begins with the admission. A warm welcoming of the patient together with the relatives who have accompanied him will be very much appreciated. The first impression they get must be that we are interested in taking care of them. Here what a patient wrote in the memory book, is worth mentioning: "I was received by the Sisters as one of their family members who came back, since long". That itself gave him a ray of hope and happiness. The patients must feel that they are in safe hands. A gentle and loving approach will make them feel at home. Give him a comfortable bed, call him by name, and find out if there is anything to be done immediately for his physical well-being, determining priorities: a) Relief of pain. b) Need for bathroom facilities. c) Preference to have a bath and change of outfits. d) Take care of hunger or thirst. e) Need for rest and sleep. f) Find out from the relatives, all his likes and dislikes.

Total care is given to the patient in order to make him feel refreshed and happy. Family members who had so willingly devoted all their time and attention to his care so far, will be relieved of their tension, anxiety, when they see that the caring team is willing to cooperate with them in the ongoing programme of caring for the patient. The basis of an ongoing programme would be:

"My patient is a broken down person - physically - mentally-psychologically - spiritually - socially and economically. My approach to the patient - by a sweet smile - calling him by name - a gentle touch - a patient listening - an empathetic approach - guidance in his spiritual needs - an appreciation of his own culture/religion - a support to his economic problems will be of much value towards the happiness of the patient".

Well planned measures must be adopted to alleviate all the distressing symptoms. Once we win the confidence of both the patient and the family, it is easy to find out their problems. Fill in the file with all the details and correct

Sr. Herta Mempra, RNRM, is working as Ward Sister in Shanti Avedna Ashram, 216, Mount Mary Road, Bandra, 400500

information. See that the relatives are aware of the present condition of the patient and the prognosis. If any one would like to stay with the patient, they should be welcomed.

Distressing Symptoms

For 70% of the terminally ill patients, the main problem is pain. The points to be kept in mind in management of pain are:

Pain is a subjective experience. There are limited objective signs to confirm the severity of pain. The best maxim is therefore "Pain is what the patient says hurts".

Terminally ill cancer patients in the hospice are visited regularly by nurses and this close and continuing contact gives the nurse a unique opportunity to observe the patient in pain and these observations will help to notice what causes exacerbations: walking, eating, or a visit from the family, etc. The patient who gets relief in pain a few minutes after taking a tablet, is suffering from anxiety, rather than purely physical pain. Some patients seem to use their pain to gain sympathy from an unsupportive family or attention from a busy nurse. So the nurse will understand that these pains are cries for help and arrange the nurses to visit the patient regularly.

The nurse can assist in raising the pain threshold:

- By good understanding and adhering to the medication regime.
- By reporting the symptoms and taking control of them;
- By making sure that the patient has a good sleep and adequate rest;
- By understanding their fear and anxiety;
- By preventing isolation and loneliness;
- By providing opportunity for expression;
- Relief of boredom: by recreational facilities by occupational therapy.
- By providing comfort by application of heat, special equipment, as required; e.g. small ball to hold in the hand, to facilitate finger movement; Wheelchair to move around; Walking stick; Walker.

Control of Physical Symptoms

Nausea and Vomiting

The nurse's role should be to control nauseous odours, prevent unpleasant sights, eliminate constipation, ensure pain control, and to see that an appropriate diet is provided. The nauseated patients will tolerate cool fizzy drinks better than tea or still drinks. Low fat food like white bread, mashed potato and savoury food can be eaten, where other sweet foods are nauseating. Small meals taken often would be in order. Food value of fluids should be stressed.

Dysphagia

Assessment of the patient with dysphagia begins with examination of the mouth. If due to oral candida, it can be remedied with proper medication. When swallowing is painful, xylocain vicuss do help when administered, sometime before liquid food. Where the lumen is partially blocked by the gradually growing tumour, it is advisable to introduce (insert) the Ryles tube in time and establish regular feeding. Where all these fail, the only way possible is a gastrostomy.

Anorexia

This is a frequent symptom and patients unable to eat adequately as their disease progresses may become fearful, because the inability to eat may be viewed as a threat to life. The patient can be freed from the pressure to eat by enhancing patient comfort through providing small appetising meals. It is important to show him that you love him, in ways other than through food. Let him sit with the family and eat what he wants. Serve small servings of the patient's favorite foods on a small plate.

Gently encourage, but do not nag; remove uneaten food without undue comment.

Mouth problems

Good oral hygiene is very important. Debris should be removed with soft toothbrush and paste, then rinse the mouth as and when required with weak potassium permanganate solution. Chlorhexidine mouthwash, listerine solution also can be used. In some patients with very smooth red tongue, vitamin deficiencies should be considered. Patients who have had a very poor dietary intake for a long time may well be Vitamin C deficient, a deficiency of B vitamins will also cause sore mouth. Oral supplementation with B or C vitamins is beneficial.

It must be remembered that physically the patient is becoming more and more dependent. It is a kindness to mask this dependence as much as possible by observation and a readiness to "share their living". Do not demand. They ask for help and acknowledge their weakness, but hide the weakness from them by help for instance offer a glass of water or a cup of tea, and keep a guiding hand nearby to prevent it from spilling on the bed, but let the patient feel that he is able to do it by himself. Nutrition is often a major issue and concern of terminally ill patients. For the total welfare of our patients, we provide nourishing food according to the taste and needs of each patient.

Though we serve food five to seven times a day, we always make it a point to enquire if anyone is in need of anything, between these hours. For instance, there can be cases where a patient was sleeping or who could not take food in time or preferred something cold after the meal time or desired to have a little fruit juice instead.

Pressure area care

Care of skin is essential, because patients with cancerous condition, in the terminal stage, often become very debilitated. There may be marked loss of

weight. It is crucial that the skin is kept clean and most patients appreciate a daily bath or sponge. Regular massaging of pressure areas is comforting and aids circulation. The use of special mattresses, alternating air beds and water beds, all play a part in protecting pressure areas. Patients should be encouraged to change position at regular intervals. As they become more immobile and perhaps confined to bed, it is the nurse's responsibility to turn the patient regularly and treat pressure areas to minimise damage.

Ascitis

The fluid in the abdomen is usually very high in protein, so there is a danger that the patient will become protein depleted when the ascitis is tapped. Ascitis tends to re-accumulate fairly rapidly after tapping. The protein depletion that occurs can result in a rapid deterioration in the patient's general condition. So it is only worth considering in patients, who have marked symptoms; such as a patient who had difficulty in sitting because of the pressure of the ascitic fluid; to nurse a patient who cannot bend in the middle can be extremely difficult - the simple withdrawing of a litre of ascitic fluid may allow the patient to be comfortable.

Constipation It can be relieved by stimulant laxative, osmotic laxative lactulose in case of a sluggish bowel from immobility. Such patients must be encouraged to take a lot of water and other fruit juices. At times when the rectum is impacted by faecal liths, it has to be manually removed before an enema can bring the stool down from the upper rectum. The patient must be given adequate analgesics prior to such procedures. A paraplegic patient should never be given an enema without first doing a gentle rectal examination, since the firm stool avoids the embarrassment of faecal soiling. Dignity must be preserved at all times.

Intestinal Obstruction This is common in the terminal stage of abdominal malignancies. This is characterised by spurious diarrhoea, abdominal colic and distention. When the obstruction is complete, the diarrhoea ceases and projectile vomiting begins. This is sometimes faeculant if the obstruction is low down in the bowel. Most patients sadly have multiple sites of obstruction and have an abdomen riddled with tumors. In such conditions, the best we can do is to empty the stomach by a naso-gastric tube.

Diarrhoea This can be managed by ruling out the cause. Malabsorption, laxative overdose, infection, G.I. bleeding, overflow in constipation. Tumours in the large bowel frequently secrete mucus and act as an irritant focus. Rectovaginal fistula, incontinence, dysuria, bladder pain, etc. have to be managed without delay, since these are very annoying problems for the patient and add to the already existing problem. Lot of fluid intake should be encouraged.

Dyspnoea This gives rise to tremendous fear and panic to the patient. Treat the cause of dyspnoea, e.g. plural effusion, tumour invading the main bronchi. Facial cooling has been shown to relieve the sensation of dyspnoea, which is why the patients feel better sitting by an open window. A small electric fan produces the same breeze most effectively.

Itch The patient's skin becomes dry and scaly with cancer Simple liquid oils and creams can be used to relieve them. Severe itching is due to liver failure. Very severe pruritis must raise suspicion of scabies - careful examination of the skin and application of Benzyl Benzoite is of help.

Fungating lesion The visible marker of disease that literally eats through to the body surface requires the most sensitive and tactful nursing care. It is so important to remember that the patient will be embarrassed by the smell of necrotic tissue, by soiling and oozing from the tumour surface and by the indignity of having a sensitive part of the body destroyed. The fungating lesions will not heal and will look worse as the tumour grows. Much can be done to keep the lesions comfortable and odourless, but the attitude with which the dressing is performed, facial expression often gives away far more than ever intended, the sensitivity throughout will do far more to alleviate the patient's feelings of shame, disgust, and alienation. The patient's sense of dignity can be maintained by gentle conversation. Dead black and grey sloughing tissue, which is a medium for anaerobic bacteria to breed and cause bad odour, should be cleared away by debridement with a scalpel blade or scissors. Cleansing with half-strength eusol or hydrogen peroxide, followed by normal saline, betadine can be of help. Any lesion which is inflamed and has an offensive smell can be dressed with flagyl (Metronidazole). A pad soaked in adrenaline - 1:1000, may be useful when capillary bleeding is present. Light absorbent guaze dressing can be prevented from sticking by soaking the layer adjacent to the surface in liquid paraffin or vaseline gauze can also be used. Dressing should be done whenever needed under analgesic cover.

Weakness Advancing disease is often accompanied by weakness and may be most distressing. Physiotherapy can help to an extent to improve the tone of the muscles and joints to facilitate movement.

Hypercalcaemia should be considered in any patient who has become drowsy, confused, constipated, nauseated and dehydrated, causing a dry mouth. Hypercalcaemia can also cause polyurea. Spinal compression due to the pressure of the tumour, especially pain in the thoracic or cervical spine region associated with leg weakness comes first.

Parkinsonism can be caused as a side effect of drugs. *Lymphoedemia, depression, fear* and *anxiety, insomnia,* are also other distressing symptoms. The first rule in treating patients is to believe the patient. Deal with the pa-

tients' requests promptly and never say "back in a minute", unless it is literally true. It is easy to forget to come back, or to be interrupted by other work and prevented from coming back. This results in a slight which is very hurtful and shakes the patient's confidence because all the time the patient needs to be impressed by the fact of being a valuable person, despite his numbered days.

All the team members should be familiar with the patient and her condition. Each one should know what to tell, when to tell, how to tell, and how much to tell. Regular ward meetings should be conducted to evaluate her quality of life. Once the pain and other distressing symptoms are controlled and also the general conditions are satisfactory, instruct the family to take him or her home for a day or two. He or she must be instructed to take the correct dose of medicine and must feel that the team and family is interested in her or him and his or her views are accepted.

The spiritual needs of the patients are met by counselling and praying with the patients. When required, we can call in the Priests, according to the patient's preference, to assist them in their need. We celebrate the birthdays of patients and other common festivals, to encourage and entertain them. Recreational facilities are provided. Those who are interested in going for a ride are given opportunities, since our volunteers are most glad to do this favour for them. Thus our patients feel it worthwhile to live with meaning in their last days.

Every person will die in their own personal way reflecting their way of life. Empathy is the ability to perceive accurately the feelings of other persons and to communicate this understanding to those we serve. At times we come across our patients who find it very difficult and frightening to face death. To be with the dying person as he goes through this last act of surrender, is to comfort him, share his last hours of loneliness and confusion, holding his hands with affection, making him feel relieved and fortifying. Though we face death every day, it is a mystery, a reality beyond understanding, since two people are not the same. It is a rewarding experience to face death with our terminal cancer patients.

Shanti Avedna Ashram

The Shanti Avedna Ashram, India's first Hospice, was started in November, 1986, at Mt. Mary Road, Bandra, Bombay. Over the last six and a half years the Institution has cared for over 2000 advanced and terminally ill cancer patients totally free of cost and irrespective of community, caste or creed.

Recently the Ashram's first Study Centre for Palliative Care for advanced and terminal cancer patients was opened. This Study Centre has been endowed by Mr. A.H. Tobaccowala, Chairman of Voltas Ltd., and members of his family as a tribute to his wife and mother. It is hoped that the Study Centre will create a keen interest in much needed Palliative Care for advanced and terminally ill cancer patients when nothing more can be offered to them in way of active treatment. We hope it will inspire many more to carry on this work in their own surroundings all over the country. The Ashram has a capacity of 50 beds and also outpatient facility. The Ashram also has a branch in Goa at Loutolim. A new branch is scheduled to be opened in New Delhi in early 1994.

At any given time, an estimated 15 lakhs of people will be suffering from cancer. Even if a fraction of this population is considered to be in the advanced stage, one can see the magnitude of the problem. Hospices alone cannot handle this. Our goal, therefore, is to see that Palliative Care reaches every corner and every home in the country. The only way we can achieve this is by training people in Palliative Care so that they can practise it in their own surroundings be it a hospital, a hospice or even home. Palliative care can be provided by people from all walks of life like doctors, nurses, volunteers, social workers, and religious and even lay people, who may be interested in looking after terminally ill cancer patients. In order to share the experience gained over the years and to train as many people as possible in palliative care, the Shanti Avedna Ashram has started its First Study Centre for Palliative Care at the Ashram. This center will have multidisciplinary courses as well specialised courses for various disciplines involved in Palliative Care.