Hold My Hand, Let Me Not Feel the Loss !

A Nursing Care Study

Mrs. PUNITHA EZHILARASU

This article outlines the care and treatment offered to a distressing, 13-year old, pre-Adolescent child, who underwent Palliative Forequarter Amputation, for Osteogenic Sarcoma. Special emphasis is laid on the way she worked through her grief, subsequent to alteration of body image.

A Child in Distress

Miss K was an emaciated girl with a pale and anguished look. She was trying to cover her huge, swollen disfigured left arm with a towel. Miss K, the only child to her parents of a middle class family, was studying in the eigth standard at the time of her admission. She was good at sports and was fond of reading fiction. It was only six months ago that she had to discontinue her studies due to her present illness.

Miss K had normal growth and development and had no history of any major illness. Her present problem became evident six months ago, while doing the Shot Put at school. She heard a snap followed by severe pain in her left shoulder. The pain persisted and the swelling kept on massively increasing. A biopsy taken in her native place (a neighboring country) revealed Osteogenic Sarcoma and amputation of the limb was advised. She had two sittings of radiotherapy for ten days.

A Life Threatening Disease

Osteogenic Sarcoma is the most frequently encountered malignant bone cancer in children. Its peak incidence in girls is 13½ years of age and in boys it is 14½ years of age. The tumour arises from osteoblasts, the most common site being in the metaphysis of a long bone, over half occur in femur and tibia, with the rest involving the upper end of humerus.

The normal features are pain and swelling. Joint function is limited as the tumour grows. Pathological fractures may take place after an erosion of the bony corten. Osteogenic Sarcoma is a tumour with a poor prognosis, since metastases often spread to the lungs. The tumour is not particularly radiosensitive. Therefore, amputation is the treatment of choice if no evidence of metastases is shown on X-ray. In cases of metastases with severe pain and deformity, amputation may be done for palliative reasons. For tumours of upper humerus a forequarter amputation (removal of arm, scapula and portion of the clavicle on the affected side) is performed. Surgery is followed by Chemotherapy.

Being a life threatening disease, Osteogenic Sarcoma results in disability, which has a tremendous impact on the patient's body image. A patient with a condition that will create a permanent disability has a multifaceted adjustment ahead. The psychological reactions which arise due to alterations in body image are similar to those seen in other crisis situations such as bereavement and lead to grieving process. Miss K not only underwent physical trauma but also had to work through an immense psychological trauma.

Journey to India

Miss K's parents decided to treat her in Vellore hoping that they would save her limb. Since her father could not accompany her due to political situation in her country at that time, her mother accompanied her.

With great hopes and expectations, Miss K was brought to India. But, alas! the hopes of the mother and daughter were fully shattered when they heard that amputation is the ultimate treatment to save her life. Besides, her prognosis was quite poor, since secondaries had already developed in the lungs.

The Child and the Family Needed Support

Miss K was very much reluctant to lose her arm. Her mother was very upset and was in tears. She was understandably anxious. It took the efforts of many senior Nursing Staff, besides the Orthopaedic Surgeons, to help the mother and the child to realise the need for amputation. For the child to accept the need for an amputation, she must be aware of the lack of alternatives to treatment.

Miss K was curious to know about the prosthesis, limitation on physical ability and prognosis in terms of cure. A sound approach is to answer the questions without offering unrealistic hopes and expectations. Since her prognosis was grave and prosthesis fitting was not advisable by the Orthopaedic Surgeons, the senior Nursing staff with greater understanding of communication, had to counsel Miss K and her mother with much concern. However, this had to be done rather cautiously. The mother and the child were reassured that though the idea of amputation was frightening, it would relieve her distressing pain.

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The Pre-Operative Period

Miss K was transfused two pints of AB+ve whole blood since her haemoglobin was found to be only 9.6 gm%. Syr. Ferrisulf was also administered to her. Her pain was alleviated by administration of Tab. Fortwin.

On September 27, 1983, she was taken for surgery and she underwent palliative left forequarter amputation. The tumour was found eroding the skin, almost fungating through skin.

The Post-Operative Period

Miss K was brought to the ward at 3.30 p.m. with one unit of AB+ve blood on transfusion. The wound was dressed and kept intact by elastoplast. She had a wound drain to minimize the build up of fluid. It required a lot of skill and tact by the senior Nursing staff in supporting the child and mother to accept the great loss.

The Grieving Process

Loss of a limb constitutes a grieving process. Before the child can realistically accept the altered body image, she must go through the usual reactions of grief such as withdrawal, depression, denial, anger, dependency, and acceptance.

On Miss K's return from the theatre, careful observations were made. Her vital signs were stable. There was no oozing from the wound. She was fully conscious but refused to open her eyes. Miss K was in the initial stage of grieving process, which is shock. Her mother was reacting by sobs. Health professionals who are aware of the normalcy of such stages can help parents understand the child's emotional reactions. These are self-attempts to cope with a loss.

Miss K was found very much upset and withdrawn, even on the next day. She refused to respond and was closing her eyes tightly. Intravenous infusion was discontinued and she was allowed soft diet. Miss K refused to eat. She cried aloud saying "Don't force me to eat, I want to die". She was undergoing severe psychological storm. We recognised this as one of the stages she would go through and although we made it clear that we were all availalile if she wanted to talk, we did not pressurise her.

Initially, when the patient is experiencing the impact of loss with its shattering effect on the ego, it will require time to begin to gather new resources and to reinforce old ones. Depression, anger and varying degrees of dependency are expected during this period.

Miss K's psychological status remained the same the next day also. She was withdrawn, resentful and refusing to eat. She began to complain about phantom pain she felt as if the limb that had been amputated was present and experienced severe pain. Phantom limb sensations may be very distressing and confusing to a child. It has been described as a hallucination in which a patient reorganizes his/her perception of body as established by kinesthetic and tactile sensations. Feelings such as burning, itching, throbbing or sharp pain may be perceived in the phantom limb Miss K was supported in understanding that these sensations are normal and will gradually decrease. She was encouraged to feel for the missing part and assisted to develop tactile sensations over the wound, as the extremity of her left upper limb. Tab Largactil 25 mg was given thrice a day to improve her mental status and Inj. Fortwin was administered for her severe pain.

Miss K seemed disinterested in life and refused to co-operate in dressing the wound until the fifth post operative day. Her wound drain was removed on the third day. Senior Nursing staff continued to afford psychological support to her. She was cheered up with bright flowers and beautiful dresses. Yet we had to wait in patience to see the change in her emotional state. At times she was found to be sobbing. It took time for her to release her feelings through verbal sharing.

As time goes on, the patient gradually comes to accept the loss. Each person works through the disability in a unique way It depends upon his/her psych logical make up and especially the support provided during the trying period. Each person must be allowed to move forward according to his/her own speed.

It was on the seventh post-operative day that to my great surprise she greeted me with a smile, sitting on a stool She looked cheerful and began to eat without much difficulty. We were glad that she was approaching the adaptation phase. As she remained very dependent on her mother she was encouraged to participate in self-care activities. After the acute phase following initial disability patient's participation becomes a key to vital psychological adjustment.

Physical Pain Reappeared

Miss K was recoveing from initial shock. She was provided with story books which she liked to read. But soon her physical problems reappeared. She developed haemoptysis, indicative of lung secondaries. She had vomiting and her appetite declined. She was offered support during this period and frequent mouth washes were given to promote comfort and a sense of well being. Her suture line union was good initially and later showed signs of infection. Tab. Septran was administered. Her temperature was shooting up. Intermittent pyrexia was treated with cold applications and administration of Inj. Acknil. She had a course of cytotonic drug therapy (Tab. Methotrexate 5 mg o.d. for 3 days). Tab Riboflavin was given for her stomatetis. Inj. Fortwin was given to relieve her from recurrent chest pain.

Ready to be Discharged

Miss K's mother was becoming increasingly anxious. The grave condition of the daughter, her intense suffering and the mounting hospital bills were

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A Case Presentation on Porphyria

Mrs. PENNAMMA RANADIVE

Introduction

In recent years cases of porphyria are being diagnosed and treated. So I thought it will be better if I share a case who was admitted in male medical ward in the month of August, 1983, treated and discharged in a satisfactory condition. This involved Nursing personnel who gained new knowledge and deeper insight of behaviour, need and approaches towards this particular patient.

Mr. 'X', 25 years old, was admitted in male medical ward of the C.M.C. Hospital, Ludhiana. He was unmarried, of wheatish complexion, of average build with good nutrition. On admission he was fully conscious. His main complaints were: (a) Abdominal pain in epigastric and periumbilical region. It was colicky, intermittent and diffuse in nature; (b) Fever for 5 days; (c) Vomitting started a day, prior to the attack of pain after consumine alcohol. Followed by pain and vomiting episode (3) for 3 days.

Initially, he was diagnosed as a case of Baralgan induced paralytic ileus. But after subsequent investigations he was finally diagnosed as a case of cute intermittent porphyria.

Porphyria is a disease of metabolism in which excessive quantities of the organic pigments, Porphyrins, are formed and also retained in the tissues.

Porphyrins are cyclic compounds containing 4 pyrrole rings which are the precursors of heme and of other important enzymes and pigments.

Heme is the complex of iron and porphyrin which unites with the protein globin to form haemoglobin. Disorders of porphyrin metabolism is due to the distrubances in the anabolic sequence of porphyrin metabolism.

Porphyrin disorders are of two types: Congenital and acquired: Congenital is hepatogenic and acquired is erythropoietic.

Acute Intermittent Porphyria

Patho-Physiology : It is hereditary due to inherited enzyme deficiencies in pair hemebiosynthesis predominantly in the liver, without affecting haemoglobin formation. Affected individuals are homozygous and it is due to the functional imbalance between the activities of uroporphyrinogen I synthetase (U.P.I.) and uroporphyrinogen III co-synthetase (U.P.III). Abnormalities seen in maturing erythroid cells and results in massive over-production of U P.I. while U.P. III production will be normal or slightly increased. U.P. I cannot be used for hemesynthesis but it is converted to co-porphynogen I, which cannot be further metabolised. They accumulate in the tissues and are excreted in excess amounts in urine and faeces.

Etiology

1. Disorder in the porphyrin metabolism which is already mentioned above and also there are certain precipitating factors as follows.

A (1) Barbiturates. (2) Anticonvulsants. (3) Oestrogen. (4) Contraceptives. (5) Steroids. (6) Sulfonamides.

B. *Alcohol :* This man consumed alcohol one day prior to the attack of pain. All these are oxidized by the hepatic microsomes.

C. Prolonged fasting.

D. Infection.

E. Psychic trauma.

F. In case of women excerbation are seen during menstrual cycle, in late pregnancy or shortly after the delivery (post-partum).

Diagnosis

Diagnosis is usually made by measuring the activity of uroporphyrinogen I synthetase in erythrocytes, lymphocytes and cultured skin fibroblasts.

Clinical Presentation

Symptoms rarely occur before puberty, initial or most important symptoms of porphyric attack is

Books description

1. Abdominal pain :
   Moderate
   Severe
   Colicky
   Localised
   General
   Radiation to back or loin
2. Abdomen—soft
   No tenderness
3. Fever
4. Nausea, severe vomiting
5. Persistent constipation
6. Leukocytosis
7. Neurological involvement can be there.
8. Urinary retension—during acute attack.
9. Excessive sweating

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tenance drip (for medication, injection) for one week.

Reassurance : Reasurance was very important to evade the anxiety and worry of his and his relatives. The relatives were told about the condition of the patient, his treatment and prognosis.

Observation : Vital signs and abdominal girth checked 2 houriy then later 4 to 6 hourly. Nasogastric Tube aspirated 1 hourly and the amount recorded. A watch was kept for abdominal pain, vomiting also. After the admission he did not have any vomiting but many times he complained of abdominal pain.

Intake and Output Chart : An accurate intake and output chart was maintained to know whether the intake was balancing with the output. Gradually, the relatives were instructed about the kind of fluid and food he should be given. A graduated measure was provided to measure the fiuids and similarly all the outputs were measured.

Personal Hygiene : A sponge bath along with oral hygiene, care of the hair, eyes and nails were given every day till he became able to do things by himself.

Elimination : An aperient was necessary to this patient to keep the bowels open and to prevent constipation and abdominal distension, mild laxatives like milk of magnesia, 30 mls, given at bed time and on August 6, 1983 glycerine enema was also given.

Bed pan and urinal offered immediately whenever he wished.

Restriction of Relatives or Visitors : Only one person was allowed to stay with him to provide necessary help and care. It was absolutely necessary to restrict visitors so that the patient had good rest and sleep.

Mr. 'X' was interested in listening to music and he was listening to the ward radio. He was provided with some reading material in which he was interested. Recreational therapy diverts the mind of the patient and relieves anxiety and worry.

Alcohol : Alcohol was restricted and he was advised not to drink any more because this was one of the precipitating factors.

Instructions Given on Discharge : He was taught about personal hygiene, importance of rest and sleep, regularity in intaking medicines, prohibition of alcohol and smoking. Observation of the signs and symptoms of repeated attack. To seek medical advice for the ailments. At the time of discharge he was on following drugs: 1. Tab. B. Complex 1 T.D.S. 2. Mist. mag. Trisilicate 15 ml. T.D.S.

He was asked to report for check-up after a week. Emphasis was given to avoid alcohol and to take rest for one week and then resume his work. After a weak he became asymptomatic, appetite was good, bowel habits were also good.

Alma Ata Declaration on health for All by 2000 A.D. can be fulfilled if we give timely education to the people specifying preventive aspects. Complications can also be minimized along with other measures.

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making the poor mother weary and helpless. It was only the emotional support given to her, which kept her moving. Financial assistance was provided from the hospital when she had to clear the bills.

On the twentysecond day Miss K was discharged. Though painful, both mother and child left the ward bravely. The emotional turmoil that the child had gone through and the way she worked through, had prepared her to certain extent to face even worse things in her life. She was advised to continue Tab. Methotrexate 5 mg o.d for 3 days every month.

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