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Vol. IX – Issue 3, Jan., Feb., March 2009
A Quarterly News Bulletin



For Private Circulation - Re. 1.00

Sr. Mello F.C.C., Chairman

Dr. R. Nanjunda Rao, President

From the editors desk

It is with much pleasure that I am writing these few lines. After the up-gradation of Jeevodaya as a Regional centre for training Doctors and nurses in palliative care we have so far trained 53 doctors and 16 nurses in palliative care in three batches. We conducted six one day work shops, three for nurses and three for social workers totaling 145 members. Many are waiting to be registered for forthcoming sessions. We feel it as a privilege that Jeevodaya could stand as a medium for training a good number of doctors and nurses who have been inspired to step into the field of palliative care.

This year also, as on the previous year, on 29th January Ms. Gilly Burn, Director cancer relief India and her palliative care tour group from different parts of Europe and Australia visited Jeevodaya as part of their educational visit to South India. They were very much impressed by the services rendered and were particularly appreciative of the permanent exhibition on cancer awareness set up at Jeevodaya.

Our Hon. Medical Director, Dr. Manjula Krishnaswamy delivered a guest lecture titled "Factors contributing to variability in response to Opioids" at the 16th National and International Conference of IAPC on Feb.15th 2009 at AIIMS, Delhi

In this issue we are publishing one of the case studies submitted by the participants of the course which is a standing evidence of how our trainee doctors and nurses have evolved in understanding, sharing and consoling their patients in their hour of pain and agony.

I would also like to express my heartfelt thanks to Mr. Ram Krishnaswamy of Sydney, Australia, a long term friend and well wisher of Jeevodaya for dedicating the book 'Reflections by IITians' published by him to Jeevodaya and offering to contribute the proceeds of the sale of the book to Jeevodaya.

The article "Holistic Care" in the last issue, was reproduced from the "Workshop Hand book - Holistic care at the end of Life" by Indian Association of palliative care in collaboration with Help the Hospices England. I apologize for the omission.

Easter is fast approaching. Jesus the redeemer of mankind came to this world to be one among us, to share our pain, to heal our illness by His healing touch and to raise us from death by rising himself from Death. Let us try to spread his Easter message of Peace and Joy to whom ever we meet. May the Peace and Joy of risen Christ radiate in all of you. .

Sr. Lalitha Teresa, FCC

Case Reflection

Note from Dr. Manjula Krishnaswamy, Hon. Medical Director and Course Co-ordinator: Jeevodaya conducts a bi-annual IAPC Certificate course in 'Essentials of Palliative Care' for Doctors and Nurses wherein the candidates are required to submit a case reflection which in turn is a reflection of their insight into their understanding of the basic principles of Palliative Care. While I would like to congratulate all the candidates for their efforts, some of which were of very high standards, one case reflection submitted by a nurse Ms. Selma Thomas a lecturer from Apollo college of Nursing – particularly impressed both the external and internal examiners – as a token of appreciation we are publishing excerpts from her article in this edition of Newsletter – Well done Ms. Selma Thomas –Keep up the good work!

Ms. R, a eleventh standard student, was the first born of four children of a Jaipur based diamond merchant. Her mother was a housewife. She was a very pretty, smart and bubbly 17 year old frequently getting customary calls from anxious classmates and friends back home. Being a close knit family, her mother a traditional housewife and her two younger sisters were always found doting and fussing over her. She was brimming with hope of a considerably long survival following BMT and getting back to her friends and family.

She had manifested with low-grade fever for over four months with fatigue, anorexia and loss of weight and occasional gum bleeding. On examination she had pallor, lymph node enlargement, increased capillary fill time > 3 seconds, tachycardia. Clinically she had decreased Hemoglobin, grossly elevated WBC counts, CD3 counts were elevated and CD19 decreased. Bone marrow aspiration and biopsy was done which revealed an increase in the immature form of WBCs.

She was diagnosed to have Acute Lymphocytic Leukemia. Though the initial diagnosis was shattering to the entire

family as 'blood cancer' was always viewed as a fatal illness, they gradually came to acceptance of the condition and after several 'second opinions' came forward for a bone marrow transplantation as a final resort.

The Pre BMT chemo had cost her hair but a bold printed scarf covered it all. The lonely moments in BMT unit prompted her to request my presence, a relatively free individual when compared to the very busy specialty nursing staff, to give her company or just listen to excited chattering of what she would do after going home.

An allogenic Bone Marrow Transplantation was planned following chemotherapy-induced remission. The donor being her 15 yr old first sibling, HLA typing was done to match the recipient, and she was equally excited about giving her sister a new lease of life.

Her chemo regime consisted of Prednisolone, Methotrexate, Vincristine, Cytarabine and L'asparaginase. She was transferred to BMT unit on the 7th day and kept until complete remission occurred following 21st day following which BMT was carried out followed by close monitoring of cell counts with supplementation of Colony Stimulating Factors and Interleukins.

After over a week of monitoring it was detected that the transplanted bone marrow had not taken up independent production with the cell counts remaining dangerously low.

After due discussions with the family members another transplantation was planned with the donor being the 13 year old second sibling.

The protective isolation was turning into a torture with the feeling of being 'shut in', with reduced interaction, special double cooked bland food and the monotonous white uniforms visiting her inside her glass cage. She was becoming more quiet and skeptical about the success of the second transplant. But her family members were still very hopeful. The second transplantation was carried out following due HLA typing and stricter isolation. She was very closely monitored as she was starting to grow weak with reduced oral intake.

Following a week of monitoring it was yet again detected that the bone marrow was not taking up independent production. Her treatment expenses had already escalated over 20 lakhs with no fruitful results. The entire family was losing hope and Ms. R refused to see or talk to anybody outside the family.

The team met once again with the family and patient to attempt another BMT with the donor being her youngest sibling – her 5-year-old brother. Though her family was contemplating, she vehemently refused telling "the previous two were a failure, there is no assurance this one will be a success. My dad has spent enough on me" and added, "I don't want my little brother to suffer. I love him a lot. Please let me die."

Her refusal for further treatment was accepted. She was transferred to a setting of moderate isolation with her family members always around. She refused to turn to my side or look at me or even talk to me when I went. Her family became more reserved in their conversation to me. She wanted all her hygienic needs and elimination needs to be met by her mother and sister only and did not accept help from us.

With a grossly suppressed immune system and neutropenia she started developing high-grade fever with chills. Broad-spectrum antibiotics were continued. Central venous catheter dressing was changed regularly under absolutely sterile conditions. Temperature changes were closely monitored. Ice cap, cold compress and tepid sponging was continued when she spiked, which invariably was present all the time. This was the only time she permitted me to give any form of care to her but still refused to respond verbally.

Petechial spots started appearing on the skin and echymotic areas were seen on the inner aspect of the upper arm where support was provided to lift her and position here. Chlorhexidine mouth wash and gargling was done to prevent gum bleeding from brushing and to promote oral care. Bowel movements were monitored, infections were prevented, and were put on a water mattress to prevent skin break down and reduce body pain. Only micro pore (paper tape) was used with care to change the central line dressing.

She was very pale with low Hb levels and very fatigued. Needed assistance even for sitting up. Her sleep cycle was grossly altered. She always looked drowsy and tired with dark circles under her eyes. Anxiolytics were administered at night.

She continued to lose weight with gradual reduction in oral intake. She developed mucositis and needed xylocaine viscous to be coated prior to taking her bland double cooked diet. She required antiemetics when nauseated. Later she developed intolerance and diarrhea following which IV fluids and TPN was started with sips of oral fluids.

She had to be placed on fowler's position to facilitate comfortable breathing. Her sister brought her Walkman and played some of her favorite songs. She was drowsy but did not seem to be deep in sleep. Her gaunt emaciated appearance with pallor made her look weaker. She had expressed her wishes to go back home but was made to understand that her physical status and suppressed immunity will not permit her long travel. She often lay with her eyes closed as though she was expecting death to occur during the sleep and she would die any time soon.

Fever continued to be very high. Urine output was almost nil and she became more and more drowsy and stopped responding to verbal stimuli. It was a Saturday and just 5 days after being transferred out of BMT unit.

The medical team always discussed the treatment options and the possible outcomes with the father and then with the patient and her mother in the presence of her father. Though being a minor she was aware of every step in her treatment.

The hematology team consisted of hematologist, medical oncologist, nurses specialized in caring patients undergoing radiation therapy, chemotherapy, BMT and aseptic central line dressing care, diet therapists, social workers, psychiatrists and chaplains.

All of them had an active role to play except social worker and psychiatrist. The chaplain visited her and the family during the terminal stages. Though Ms. R carried a hostile attitude towards the chaplain, her mother still held on to a slim hope. Her mother often said "I have prayed to all the gods, will my daughter get better, if I prayed at the hospital chapel?"

"People back home have always appreciated the care provided here and gave us so much confidence about my daughter's recovery, but it did not happen to her."

"How is that the others who underwent BMT with my daughter are better now and she alone is dying?"

"May be we should have tried once again with my son's bone marrow. He is a strong boy."

All I could do was only listen to their venting, as I was not sure if spiritual counseling would help at that state.

Sunday being a holiday, I returned back on Monday to see her empty room. I was told she had passed away peacefully the previous evening with all her immediate family members around.

I happened to meet her father a week after. He had come to collect the final bill for a refund, a discharge summary and other records. He seemed composed but still went to see the empty corner room in which his daughter was during her last days.

CONCLUSION

As far as my learning needs were concerned, Ms. R was an excellent case to learn from, I was able to see a classic case of ALL undergoing BMT, having a failure and meeting her end with all the clinical features to support the book picture. Every time I teach my students on nursing care of patients with leukemia, I am able to use her case summary (without due permission) and the long period of care has also helped me build my communication and counseling skills along with the skills required to provide the best possible nursing care.

I was further able to identify the ethical issues and how it had been handled concerning patient's wish to refuse treatment and when in spiritual distress, the intricacies in communicating to the patient and significant others the illness as well during the terminal stage, the grieving process, the patient had gone through, from denial - anger - bargaining - depression - acceptance and resignation, the relatively peaceful path her life took during the terminal phase from sleepiness - lethargy - obtunded - semicomatosed - comatosed and death finally and the inevitable role of every health team member in providing the best possible care through a multidisciplinary approach and the importance of symptom management to facilitate a less traumatic last stage. I still feel, better communication skills and appropriate spiritual support would have promoted the quality of life of Ms. R.

But on the personal front, every time I talk about leukemia, her cheerful bubbly pretty face flashes in front of my eyes. Though I believed in miracles, I was not able to give the kind of hope expected by a mother when her first-born was terminally ill.

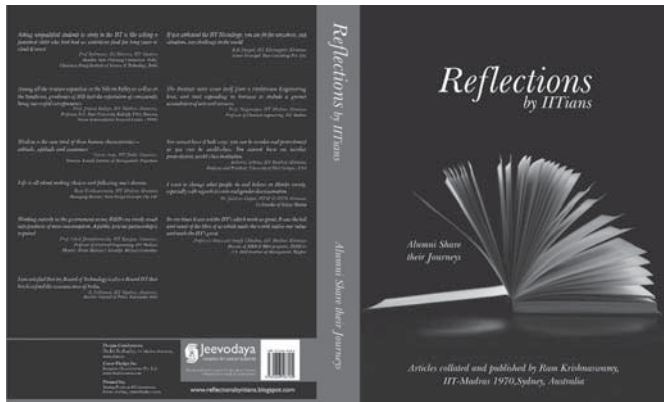
Being a sensitive person, Ms. R did affect me emotionally, which taught me to build an emotional shield around me to protect myself when I cared for such patients later.

As a nurse I don't know in what way I may play a role in changing policies, but in my own small way I may be able to influence my students, the future nurses, to develop the interest and understanding in caring for the dying and let them live their last days in optimal or rather maximal dignity and also extend their support to the significant others.



“Dr. Nanjunda Rao, President, Jeevodaya along with the successful candidates of the November 2008 batch of the IAPC Certificate Course.”

Announcements



1. ‘Reflections’ is a collection of 36 articles by well known alumni of IIT who share their rich experiences and ideologies in their journey through life. It makes for some very interesting and thought provoking reading. The articles have been collated and published by Mr. Ram Krishnaswamy, from Sydney, Australia, himself a past student of IIT Madras. The book was officially released on Dec.19th 2008 at IIT Madras, during the PAN IIT meet, by the well known scientist Mr. Anil Kakodkar, Chairman, Atomic Energy Commission, India and who was recently conferred the prestigious Padmashree Award by the Govt. of India. We are extremely grateful to Mr. Ram and all the authors for their kindness in offering to donate the proceeds of the sale of the books to Jeevodaya.

The books are available for sale at Jeevodaya for Rs.450/- [Rupees Four hundred and fifty only] by cash or cheque drawn in favour of “Jeevodaya”. If you need

them to be sent by post [within India only] add Rs. 80/- [Eighty only] as handling charges and send it to

“Jeevodaya”
C/o Mr. Satish Kumar,
“Sterling Prints” No.37, Nerkundram Road,
Vadapalani, Chennai 600026.
Phone -044- 23622616, 23622613,
Mobile -[0]9841010034

2. The IAPC Certificate Course in ‘Essentials of Palliative Care’ for 2009 starts on 1st June, 2009. It is an 8 week distance learning course with a 3 day contact session at the end of 4 weeks and evaluation after 8 weeks. Doctors with MBBS, and qualified nurses can apply. Dental Surgeons and House Surgeons are eligible to apply. Completed application forms, along with a DD for Rs.1000 [one thousand only] drawn in favour of the ‘Indian Assn. of Palliative Care’ payable at Calicut and a photocopy of the qualifying certificate should reach Jeevodaya by the 1st of May,2009. Seats are limited and will be allotted on a first come first serve basis. Application forms can be downloaded from www.palliativecare.in