

Seminar on Paediatric Palliative Care For Nursing Students

**On 3rd May 2019
At Faculty of Nursing,
Sri Ramachandra Institute of Higher Education and Research
Porur, Chennai, India**

**Organised by
Golden Butterflies Children Palliative Care Foundation**

**In association with
Faculty of Nursing & Department of Paediatric Oncology, SRIHER**

**With the support of
Ms. Supriya and CAN KIDS**

Scientific Agenda

Time	Duration	Topic
9.00 am	20 mins	Inauguration
9.30 am	45 mins	Overview of Paediatric Palliation Care Dr. Julius Scott Prof and HoD Department of Paediatric Oncology, SRIHER
9.45 am	15 mins	Tea break
10.00 am	30 mins	Communication as a key to care Dr Arathi Surendranath Senior Consultant Radiation Oncology Integrated Cancer Care Group
10.30 am	30 mins	Pain management in Paediatric Palliation Dr Rejiv Rajendranath Senior Consultant – Medical Oncology Integrated Cancer Care Group
11.00 am	30 mins	Symptom Management - Nursing Aspects Dr Anita David Reader & HoD, Department of Paediatric Nursing, Faculty of Nursing, SRIHER
11.30 am	60 mins	Case Studies Discussion Moderator – Dr. Latha M. Sneha, Asst Prof. Department of Paediatric Oncology, SRIHER Panelist- Dr. Arati Surendranath Dr. Rejiv Rajendranath Ms. Aneka Paul, Trustee Golden Butterflies CPCF Ms. Supriya, Parent Ms. Geetha, Lecturer, Faculty of Nursing, SRIHER Ms. Yamuna, Staff Nurse, Department of Paediatric Oncology, SRIHER
12.30 pm	20 mins	Feedback Students
12.50 pm	10 mins	Vote of Thanks Ms. Nandhini Sundar, Trustee Golden Butterflies CPCF

Report of the Seminar on Paediatric Palliative Care

A Seminar on Paediatric Palliative Care was organized on Friday, 3rd May 2019, by Golden Butterflies Children's Palliative Care Foundation, Chennai and Sri Ramachandra Institute of Higher Education and Research, Chennai. The event was held at the Basement Auditorium, Sri Ramachandra Dental College and Hospital, between 9am and 1pm, and was well attended by 164 nursing students (of 3rd year BSc, 2nd year PCBSc, and 1st and 2nd year MSc) along with their faculty. Financial support for the seminar was provided by Can Kids.. Kids Can, New Delhi and a care giver.

The programme began with an invocation, singing the University song and the lighting of the kuthuvillaku. Dr. Anita David, Reader & HOD, Department of Paediatric Nursing, SR College of Nursing, SRIHER welcomed the audience to the seminar, and Dr. S. J. Nalini, Professor & Principal, SR College of Nursing delivered the key note address. Dr. Julius Xavier Scott, Professor & HOD, Department of Paediatric Oncology, SRIHER gave a special address, highlighting the purpose for the day's seminar. Dr. Hemal Kanvinde, Trustee, Golden Butterflies CPCF informed the gathering about the NGO's objectives, through a short film, and Mrs. Shanmuga Priya, Lecturer, Department of Paediatric Nursing, SR College of Nursing, SRIHER proposed the vote of thanks.

The inaugural session was followed by the scientific session. Dr. Julius Xavier Scott gave a talk titled "Overview of Paediatric Palliative Care", wherein he emphasised the role of nurses as second mothers to a child-patient, and the need for them to communicate with the child-patient's parents/ family/ caregivers, including providing bereavement care. Being careful to not give false hope but to help cope instead, actively listening to the caregivers, and assisting the caregivers to relieve distressing symptoms until the very end, all the while aiming to care not cure were advised. A study carried out at SRMC to learn parent's perspective of care provided during the end of life of their child, was shared. Dr. Scott lamented the absence of fully functional paediatric palliative care departments in any hospital in India, as well as the lack of systems to enable homes as patient's preferred place of death.

Dr. Arathi Surendranath, Senior Consultant – Radiation Oncologist, Integrated Cancer Care Group, presented "Communication with Children and Families as a Key to Care". She highlighted that open communication facilitated acceptance of palliation and early referrals to palliative care, leading to comfort for the patient and better psychological health of the caregivers upon eventual bereavement. Involving the child-patient in prognostic disclosure, treatment plan and end of life

care planning, according to his/her developmental age, and with parental consent, was emphasized. Practical tips such as asking open ended questions, showing empathy and concern, being culturally aware, avoiding medical jargon, and clarifying the patient's/ caregiver's understanding by asking them to repeat what was explained to them, were shared.

Dr. Rejiv Rajendranath, Senior Consultant – Medical Oncologist, Integrated Cancer Care Group, engaged with the audience while presenting “Pain Management for Paediatric Palliation”. Starting from the iatrogenic pain child-patients suffer at the diagnosis stage, he explained the need to objectively assess pain using age-appropriate scales in order to treat the pain and assess the effectiveness of treatment. The WHO step ladder for use of analgesics, drawing up Personalized Pain Goals for patients, and use of non-pharmacological therapies to alleviate pain, were touched upon. An overview was given of commonly used analgesics, their side effects and toxicities, dose titration and frequency, breakthrough pain, withdrawal symptoms and overdose situations.

Dr. Anita David gave a detailed lecture on “Symptom Management in Paediatric Palliation – Nursing Aspects”. She provided in-depth information on most of the common distressing symptoms experienced by child-patients due to the illness or treatment thereof, as well as nursing measures to combat them: both physical symptoms like nausea & vomiting, diarrhea, constipation, mucositis & xerostomia, anorexia & cachexia, thrombocytopenia, dyspnoea, anemia, etc as well as behavioural issues like anxiety, irritability and agitation.

The final session for the day was a panel discussion based on 4 case studies from the paediatric ward of SRMC, moderated by Dr. Latha M. Sneha, Assistant Professor, Department of Paediatric Oncology, SRIHER. The panellists were: Dr. Arathi Surendranath, Dr. Rejiv Rajendranath, Mrs. Supriya (a bereaved parent), Mrs. D. Geetha (Lecturer, Department of Paediatric Nursing, SRIHER), Ms. Yamuna (Senior Nurse, Oncology Nursing, Sri Ramachandra Hosptial), Ms. Hari Belsi Amudha J. (Phycologist, Can Kids.. Kids Can, Chennai) and Ms. Aneka Paul (Trustee, Golden Butterflies CPCF).

The case scenarios highlighted several important issues that had been touched upon during the morning sessions:

1. Open communication with adolescent patients about their disease condition/ treatment plan/ palliative care.
2. Legality about discussing treatment plans over text messages with patients, and the dilemma of health professionals wanting to build rapport with patients while maintaining professional distance. Hospital policy of having a common helpline number was cited as a way to circumvent this.
3. Influence of religious views and pressures from extended family on decision making by the parents on the child-patient's plan was cited, along with the need for health care personnel to respect and not ridicule decisions made emotionally.

4. The role of the primary physician in explaining to caregivers and patients the purpose of referral to a specialist and the limits of scope of the specialist was defined.
5. The importance of good symptom management, even at the last days of life, was mentioned as leaving a positive memory in the minds of the caregivers.
6. The reluctance of caregivers to consult a psychiatrist/ psychologist/ counselor, possibly due to the stigma attached to the same, was discussed.
7. Methods being experimented in other parts of the country to promote shared caring at home towns of patients were illustrated.
8. Palliative care being synonymous with pain relief and therefore including measures such as SOS stock of morphine for breakthrough pain and use of single dose radiation to relieve pain was discussed.
9. Efforts were made to understand the practice followed by the SRMC nursing staff for each situation, particularly facing existential questions from caregivers and becoming emotionally drained themselves. Spaces available for nurses to grieve, vent and manage stress were explored.
10. The role of nurses in going between the treating physicians/ consultants and the parents/ caregivers was emphasized.

All speakers were felicitated and students received participation certificates. Student representatives from BSc, PCBSc, and MSc spoke about the elements of the seminar that impressed upon them the most. The seminar ended with a vote of thanks by Ms. Nandini Sundar, Trustee, Golden Butterflies CPCF, followed by lunch.

A few pictures of the seminar

