

# **ALL SPECIAL INTEREST GROUP REPORT:**

## **IAPC**

### **Integrating palliative care in the practice of primary care**

**Co-ordinators: Dr.Srikanth. Y. Atreya (srikant.atreya@tmckolkata.com)**

**Dr. Jennifer Mugesh (jenifermugesh@yahoo.com)**

**Members include:** Jenifer Jeba, Shrikant Atreya, Sulagna Chakraborty, Nikki Pease, Ann Thyle, Alka Ganesh, Gayatri Palat, Lulu Matthew, Sahaya Anbarasi, Raman Kumar, Mary Ann Muckaden, Alan Barnard, Mhoira Leng, Dan Munday, Scott A Murray.

The members met during IAPCON 17, Coimbatore, and decided to take forward the move to meet palliative care needs across the country. For this, a joint position statement by the IAPC and AFPI-‘The way forward for developing community based palliative care program throughout India: policy, education and service delivery considerations” is being produced and is in the final stages of publication.

CME’s have been conducted by Dr. Shrikant. Y. Atreya in April’17, in Kolkata, to improve awareness and equip family physicians and general practitioners in the community. There is a proposal to start a training course for lay people (physician assistant) to be able to provide home based care for the sick under the supervision of family physician.

### **Indian College of Palliative Medicine (ICPM) - Activities 2017.**

**Co-ordinator: Dr. Naveen Salins (naveensalins@gmail.com)**

- Creation of the ICPM concept note by Dr. Naveen Salins. Publication of the concept note as the Editorial in IJPC

- Securing the seed grant and support from the NS Foundation for setting up the ICPM
- Creation of the expert committee for setting up the ICPM and planning the first meeting of the expert committee on 24<sup>th</sup> Feb 2018.
- Creation of the draft trust deed of the ICPM for discussion in the expert committee meeting and the IAPC AGM.

## **End of Life Care - ELICIT/IAPC Activities 2017**

**Co-ordinator: Dr. Nagesh Simha (nagesh.simha@gmail.com)**

- Consultative meeting on End of Life Care and signing the Mathura Declaration
- Multi-city public advocacy consultative meeting on End of Life Care.
- Creating ICMR Commission definitions for End of Life Care
- Completion of the feasibility survey on implementing integrated care plan for the dying in the Indian context and publication of the results in the IJPC
- Planning a multi-centric RCT to test effectiveness of the integrated care plan in the Indian context.

## **RMI training – Activities 2017**

- Operational guidelines of MOHFW recognises 7 courses for RMI training eligibility
- Those who have not undergone these courses it has created a 21-hour course for RMI training (14 hours of theory + 7 hours of practical)

## **Minutes of the Research workshop of the 24<sup>th</sup> International Conference of the Indian Association of Palliative Care**

A workshop was conducted on 9/02/2017 in Coimbatore which was attended by Dr. Reena Nair, Consultant Haematologist, Tata Medical Center, Kolkata Dr. Medha Joshi, Head Librarian Sciences, Tata Memorial Centre, Mumbai Dr. Abhiram Kasbe,

Associate Professor, Department of Community Medicine, BYL Nair Hospital, Mumbai.

Dr. Shrikhant Atreya conducted this 14 member workshop with the following goals:

- Inculcate the principles of research in every participant so that ideas get transformed into a good concept note at the end of the workshop.
- Develop concept notes which could be transformed into a good research proposal.
- Develop taskforce for initiating a multi-centric study from the studies discussed in the workshop.

Content included: How to write a research proposal, how to derive sample size and identify the appropriate statistical tool for study, Literature search including Boolean logic and hands on search using various Boolean logic and parenthesis

### **Future Plan for the workshop:**

- Develop taskforce for research
- Develop protocols with the help of the taskforce to develop multicentric studies- with this regards Dr. Anuja Damani, Assistant Professor, Department of Palliative Medicine, TMH Mumbai has proposed a multi-centric study on “Prevalence and Management Of Dyspnoea Interfering With Daily Life Activities In Ambulatory Patients With Advanced Cancer: A Multi-center Observational Study”.

### **The institutions that have expressed interest include Tata Memorial Hospital, Mumbai (Principal Site)**

- Tata Medical Center, Kolkata
- St. John's Medical Hospital, Bangalore
- MNJ Cancer Institute, Hyderabad
- GCRI, Ahmedabad

- Amrita Institute, Cochin
- Kidwai Memorial Institute of Oncology, Bangalore
- Cytecure Hospital, Bangalore

## ICMR Report

**Co-ordinator:** Dr. M.R Rajagopal (chairman@palliumindia.org)

Here are a few lines on it. The final document is likely to come out any day and if it comes out well before IAPCON, I shall inform you so as to modify the annual report if possible.

A major reason for the current sad reality of inappropriate end of life care in intensive care units in India is the lack of clarity and of legislation on the matter. Confusion regarding terminology, particularly between withdrawal of artificial life support and passive euthanasia, riddled attempts at all solutions to the problem including the proposed draft law on end of life care.

During the National Bioethics Conference at Pune, Dr Saumya Swaminathan, the then-director general of Indian Council of Medical Research, agreed to my plea for official definitions of related terminology by ICMR. Subsequently, ICMR created the definitions, Dr Naveen Salins taking on the lion's share of the work and Dr Roli Mathur leading it in ICMR. The work has been completed and the official document is expected to be released any day.

### Early Palliative Care India - Special Interest Group

**Introduction:** “Early Palliative Care India - Special Interest Group” (EPC-I-SIG) is a voluntary association of doctors, nurses and researchers interested in early palliative care integration in oncologic treatment.

The **mission** of the “Early Palliative Care India - Special Interest Group” (EPC-I-SIG) is to facilitate conduct of Early palliative care research across the country. Specific objectives to this SIG include facilitate integration of Early palliative care in oncology

and establishing research priorities and networks. In addition, the group plans to pool resources with other palliative care SIGs to most efficiently achieve shared objectives.

**Activities** in this group will include sharing research ideas, streamlining multi-centric trials, sharing tools and outcome measures, discussing practical barriers and ethical concerns in early palliative care research.

**Communication:** members of the group can contact other members through e-mails, Skype meetings.

**Members:** This SIG invites members who are interested in research in early palliative care in Oncology. Membership with IAPC is must to join this group. Those who wish to join, kindly mail the request to [epcsig@gmail.com](mailto:epcsig@gmail.com)

## **Palliative care and end of life care for the elderly**

- *The Indian Academy of Geriatrics (IAG).*
- *Alzheimer's and Related Diseases Society of India (ARDSI).*
- *HelpAge India.*
- *Indian Association of Palliative Care (IAPC).*

**Co-ordinator: Dr. Stanley Muckaden ([stanmac@gmail.com](mailto:stanmac@gmail.com))**

In India, the ageing population now stands at 100 million and is expected to grow to 324 million by 2050. More than 3.7 million are with Dementia. 51% of elderly are below poverty line and 73% are illiterate.

Appropriate and effective management of symptoms (pain, breathlessness, fatigue, depression, and other distressing problems) in the advanced stages of disease is often lacking; this results in poor quality of life and loss of dignity.

Too frequently, older people with terminal illness undergo unnecessary investigations, treatments, hospitalizations, and admissions to intensive care. This is burdensome and expensive for the patient, family, and society.

Access to high quality palliative care for older people with serious life-limiting illness, and closer interaction between geriatric and palliative multidisciplinary teams, can enhance the quality of lives of these people and importantly reduce costs incurred by the family and the nation. The families, who are the cornerstone of any palliative care programme, will also be empowered to care and cope during this difficult situation.

**We call upon the Indian government to ensure that every older citizen with advanced life limiting diseases including cancer and various forms of dementia, is offered the best possible palliative and end of life care wherever they are cared for.**

**Children's Palliative Care (CPC),  
Special Interest Group (SIG), IAPC  
Report, 2017-2018**

**Co-Ordinators:** Dr.Gayatri Palat (gpalat@gmail.com)

Dr.Mary Ann Muckaden (muckadenma@tmc.gov.in)

SIG of CPC is a subgroup of IAPC consisting of more than 200 members. The members are different stakeholders who are working in the field of providing care to children with life limiting illnesses. It is an informal group with no formal membership procedure but it is heartening to see the growing number of people joining the group clearly reflecting the growing interest of health care workers in paediatric palliative care.

SIG-CPC has played a significant role in increasing the awareness, advocacy, training and education. A recent increase in trend of research papers related to CPC appearing in leading journals is encouraging. CPC-SIG has managed to foster relationship with the Government, national bodies like Indian Academy of Paediatrics and its research sub group called InPOG to increase the scope of paediatric palliative care in the country.

A few focused activities of the year:

### 1. Strategic Planning Meeting

- Jointly held by Palliative Care Subgroup of InPOG and Special Interest group of Indian Association of Palliative Care, Pre-conference meeting, IAPC conference, February 9, 2017 Coimbatore.
- SIG-CPC meeting, Sri Gangaram Hospital, Delhi, 21<sup>st</sup> February 2018

### 2. Pediatric Palliative Care Workshop

- EPEC Pediatrics Pre-conference workshop, February 9, IAPCON 2017, Coimbatore
- Pediatric Palliative Care Conference, November 5,6, 2017, AIIMS, organized by Department of Onco-anesthesiology and Palliative Medicine, IRCH, AIIMS; InPOG Palliative Care Subcommittee; and CANKIDS
- Pre-conference Workshop, IAPCON, Integration of palliative care in pediatric/neonatal intensive care, Sri Gangaram Hospital, Delhi, 21<sup>st</sup> February, 2018.

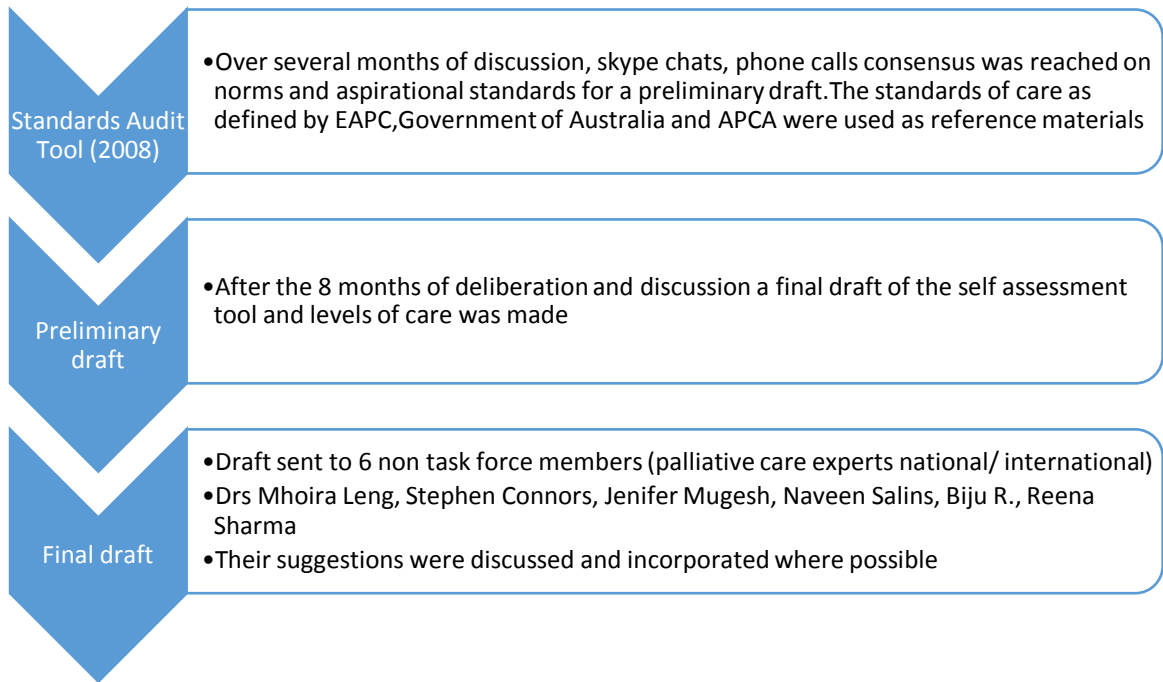
3. Networking meeting with Indian Academy of Pediatrics(IAP)- Dr Muckaden attended a meeting of IAP – CPC special interest group at Delhi

## **Task force convened by Indian Association for Palliative Care to revise and update Standards Audit Tool (2008)**

**Co-ordinator: Dr. Anjum Joad (anjumjoad@gmail.com)**

**Members Include:** Dr. Anjum K Joad, Shobha Nair, Charu Singh, MR Rajagopal, Dr Firuza Patel, Odette Spruyt, Geeta Joshi, Savita Butola, Madhura Bhatwadekar, Dineshchandra Goswami, Savita Luka Arun Ghoshal.

## What was done?



**Results:** Standards Audit Tool (2017)

## What next?

Task force meeting during IAPCON 2018;

Pilot and validation studies of the tool;

Dissemination of results.

The standards need to be seen as aspirational standards and norms. The document is an evolving one as is our specialty and must be revised and upgraded as our services mature and needs of the country and our population change.

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