

## ORAL PRESENTATIONS

### OD-01

#### INTEGRATING PALLIATIVE CARE WITH ONCOLOGY SERVICES CAN IMPROVE END-OF-LIFE CARE IN CANCER PATIENTS

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**Background:** Cancer patients with limited life expectancy are often prescribed active cancer directed therapy. The WHO has emphasised the integrated approach to palliative care in the treatment of cancer patients. The present study is an audit at a centre in North India (PGIMER, Chandigarh) where palliative care is integrated with the oncology services with the aim to see the number of patients who received antineoplastic treatment in the last 30 days of their lives.

**Methods:** Case records of all patients registered in the palliative care clinic, who died during the period November 2013 to October 2014 were retrospectively analysed. The demographic data and treatment records were analysed to record the treatment delivered, during the last 30 days of their lives. Mean duration of survival from the time of diagnosis was calculated by Kaplan Meier method.

**Results:** During the study period of one year, 970 patients were registered in the palliative care clinic and 89 patients died. The overall survival was 20 months. Majority had stage III and IV disease at presentation, and 33 patients were given palliative care within 3 months of diagnosis. The mean duration of palliative care in this group was 3.3 months. The patients who received longer palliative care were satisfactorily relieved of cancer pain. In the last 30 days of their lives, 7 of 89 patients had received cancer-directed therapy: palliative RT in 5 patients and palliative chemotherapy in 2 patients.

**Conclusion:** Early integration of palliative care into cancer treatment can improve end-of-life care by providing symptom relief without futile and toxic antineoplastic therapy. One should choose judiciously between offering only palliative care or palliative care integrated with cancer-directed therapy in advanced stage cancers with limited life expectancy.

**Key words:** Audit, End-of-life care, Integrated approach

### OD-02

#### TO ENGAGE IN CREATION OF AN INSTITUTE TO EXCEL IN SUPPLYING PALLIATIVE CARE SERVICES IN PUNE

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**Background:** Presently, the supply of palliative care services is not well defined in Pune. Palliative care patients are admitted in several multispecialty hospitals. Patients come from far and wide to see the physicians at the hospital as an outpatient. Sometimes, they get admitted in the ward for acute treatments. When their status changes to palliative care, they are discharged and sent home with no possibility of an organized home care service to bring comfort to the patients and their family members. Some families can afford to keep their loved ones in the hospital. Many cannot afford to do that due to lack of finances or resources. These palliative care patients need and deserve properly organized services to keep them pain-free and comfortable at the end of their lives. I would like to engage in the creation of a Palliative Care Institute (PCI) in Pune. The PCI will have the following structure: reception, physicians, nurses, physiotherapists, occupational therapists, rehabilitation services, respiratory therapists, psychologists, spiritual services, social workers, volunteers, home care services, education of medical students and other health care workers, mentoring, administration, advertisement and marketing, and international connections.

The incoming telephone calls to this PCI will be from physicians and nurses of various Hospitals and from families of patients needing palliative care services. A telephone conversation with a Triage Nurse will identify the needs of every individual case. An appointment will be arranged to assess individual patient in an Outpatient Department (OPD) of this PCI. After the OPD assessment, the patient will be referred to any of the following services: OPD, home care services or inpatient services at Cipla Palliative Care and Training Centre.

In summary, I would like to ENGAGE in creating a Palliative Care Institute in Pune. I would like to EDUCATE the physicians, nurses, administrators of various existing hospitals, medical Students and the general population. This will help to EMPOWER the remediation of the present situation of lack of such organized services. Most importantly, I would like to EXCEL in supplying such health care services to our dear loved ones who are at the end-of-life stage.

### OD-03

#### HOUSEHOLD POVERTY REDUCTION THROUGH PALLIATIVE CARE: A PILOT STUDY

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**Background:** Inequality in India results in poverty being a major issue. In 74% of households the highest earning member earns less than Rs 5,000 a month. Nearly half of rural households depend on casual labour. Staff working with the Emmanuel Hospital Association (EHA) palliative care services have noted that patients and families overspend on ineffective treatment and are unaware of government subsidies and benefits. A pilot study was undertaken to ascertain whether palliative care can contribute to household poverty reduction.

**Methods:** Participants were palliative patients and their families at 3 EHA hospitals in Uttar Pradesh where palliative care services were initiated from 2010. The principal investigator administered a pre-tested questionnaire to 129 participants.

**Results:** Enrolment in the palliative care service reduced monthly expenses on medicines and travel for 85% of participants by home-based care provision, good symptom management, and provision of subsidised or free medicines. All patients reduced outpatient visits. Of these, 36% did so from direct benefits of the programme and 20% reduced hospitalization. Both contributed to patients saving on high travel costs. 8% of palliative patients earned again from health improvement. 10% of family members started working again through support and respite. Palliative care teams informed patients and families of government benefits, helping with requisite forms and documents. One team educated 171 village heads with a 5% increase in palliative patients receiving government benefits.

**Conclusion:** Palliative care has great scope to reduce desperate poverty resulting from chronic illness. Early diagnosis followed by immediate enrolment in a palliative care service contributes to household poverty prevention. EHA's palliative services are well positioned to refine the model and research further its effects on household poverty and on hospital economics.

**Key words:** Awareness, Home-based care, Household poverty, Palliative care

#### OD-04

### MULTIDIMENSIONAL PALLIATIVE CARE NEEDS IN HIV-POSITIVE PATIENTS: A PROSPECTIVE CENSUS

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Following the advent of HAART in the 1990s, HIV began to be viewed as a manageable chronic illness, as opposed to the pre-ARV era when it was a universally fatal disease always requiring palliative care. While HAART has proven to significantly improve life expectancy, studies have shown that

it does not always lead to improved psychosocial wellbeing, and sometimes results in an adverse effect on quality of life (Park-Wyllie, 2007). The association of HIV with physical symptoms such as nausea and fatigue as well as psychological symptoms such as depressed mood and anxiety (Harding R., 2012), compounded by social ostracisation, provides a unique opportunity for the integration of Palliative Care and disease-specific treatment to alleviate suffering and maximize quality of life. A prospective census was carried out over a period of two weeks, to record the presenting complaints of HIV-positive patients in Latur, Maharashtra. The physical complaints, psychosocial problems and disclosure status was noted for 283 patients during this time frame. Patients who had complex physical, psychosocial or spiritual needs were identified as those who would benefit from palliative care. The mean patient age was 37.17, and 23 patients were under the age of 16. Males were slightly more than females (143 males to 140 females) and ART was being prescribed to 253 patients. The mean CD4 count was 326 cells/mm<sup>3</sup>. Only 4.6% (13 patients) had disclosed their HIV status to their community, while 6.71% (19 patients) had not even revealed their status to family members. Of the 283 patients, 116 (41.13%) were identified as having palliative care needs. This compares with 52.9 % in a similar study in Tanzania (Harding R., 2008). Palliative Care is an integral component of “best possible care”, and is a recognized right of all people with a severe illness (Brennan, 2007).

**Key words:** HIV, Maharashtra, Palliative care, Prospective census, Psychosocial needs

#### OD-05

### EVALUATION OF PALLIATIVE CARE ORIENTATION PROGRAMME FOR MEDICAL INTERNS

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**Background:** Medical Council of India envisions that an Indian medical graduate should be able to understand and provide palliative care appropriately and effectively. In this regard, our department has signed a Memorandum of Understanding with the Tamil Nadu institute of Palliative Medicine to provide community-based palliative care in our field practice areas. Hence, we are in the process of training health professionals in palliative care. With this background, we wanted to evaluate the palliative care orientation programme conducted for medical interns.

**Methods:** A one-day orientation programme on palliative care is conducted for every batch of medical interns posted in Community Medicine by faculties trained in palliative care. So

far, three batches (52 interns) have attended the program. The sessions include introduction to palliative care, management of pain, community participation and nursing issues. A retro-pre-feedback and self-reflection using open-ended questions were collected from the medical interns at the end of each programme. Quantitative data was entered and analysed using the software Epi Info™ version 3.43. Content analysis was done with the qualitative data manually.

**Results:** All the sessions in the orientation program were well received by the medical interns and were found to be statistically significant ( $p < 0.0001$ ). The medical interns expressed their interest to undergo training and provide Palliative care to the suffering people in the community. Also they came to know the role of doctors in providing palliative care.

**Conclusions:** The orientation programme served as a successful platform for sensitizing medical interns about the need for and their future role palliative medicine.

**Key words:** Medical interns, Orientation, Palliative care

#### OD-06

#### BURDEN ON THE WIVES OF RENAL PATIENTS

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**Background:** The lifestyle restrictions on renal patients undergoing dialysis and post-transplant have significant impact on their wives too. They have to cope with the responsibility of running the household and attending to the various needs of the patients. They undergo emotional struggle of adjustment as well. The present study is to evolve ways to help them meet their needs to do well, amidst this chaos.

**Methods:** Semi-structured, face-to-face interview with the wives of 25 renal patients registered with PPCS, Thrissur was conducted, during their visit to the OPD. The interview followed key themes that explored: Daily chores and financial burden, impact on relationships, emotional and psychological issues of the wives, social impact, and role of religious beliefs.

**Results:** All the wives had to take up the responsibility of running the household with the additional burden of taking care of patients falling on them. The study revealed that this sudden change initially turned the wives to despair but eventually, they have drawn inner strength to cope with the issues. Two had to take help to fight depression and the thought of suicide. 68% received financial support from community. 16% of the couples were found to have problems in the relationship.

**Conclusion:** Arrangements for volunteers to meet the wives when they visit the OPD, once weekly homecare visits by volunteers to homes of renal patients, monthly meeting of a group of volunteers, counsellors, renal patients and caregivers all provide them outlets to vent the feelings and problems. Activities like volunteer visits to dialysis centres, helpdesk to provide information on government and social welfare matters and follow up on them, conducting awareness classes for students, mobilising funds, etc. can bring together community to get their needs met.

**Key words:** Dialysis, Patients, Renal, Transplant, Wives

#### OD-07

#### PALLIATIVE CARE TRAINING AT PATIALA, PUNJAB

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**Background:** Based in New Delhi, CanSupport has been providing home-based palliative care to cancer patients at no cost since 1996. This helps to reduce their suffering and increase quality of life. As the number of cancer patients continues to increase, so does the number of people in need of supportive palliative care services. CanSupport was requested by the Government of Punjab to provide palliative care training to Patiala-based Punjab Civil Medical Service doctors, nurses, and selected faculty members of Government Medical College, Patiala. This programme was funded by the Punjab State Government.

**Methods:** The Pilot Project was organized into three separate phases, each with its own training purpose and goals. Phase 1 (3 weeks at Mohali): Theory training, allowing trainees to become well-versed in the basics of palliative care. Prof. Mary Muckaden from Tata Memorial Centre led the phase 1 training. Phase 2 (4 weeks at CanSupport, Delhi): This was an observation period in which trainees shadowed doctors, nurses, and counsellors from CanSupport's homecare staff and learnt from their work. Phase 3 (12 weeks at Patiala): This was designed to allow trainees to put their training into practice by administering palliative care to patients in Patiala District under the guidance of CanSupport trainers.

**Results:** This 19-week programme enabled palliative care to become integrated into the healthcare infrastructure of Patiala District. As a result of this training in Patiala, following Palliative Care Services have started:

1. Palliative Care OPDs at Block HQs and at Medical College Hospital
2. Indoor Palliative Care Facility at Medical College Hospital
3. Home-based Palliative Care facility in the whole of district.

**Conclusion:** Initiatives like this can help palliative care reach the unreached.

#### OD-08

### ASSESSING THE NEEDS AND COMPLEXITIES OF PAEDIATRIC HIV IN DELHI

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**Objective:** Although there are an estimated 200,000 children (18 and younger) living with HIV/AIDS in India, little research has been done on the specific needs of HIV-positive children and their caregivers. This study's primary objective was to determine the needs of HIV-positive children and their caregivers in Delhi.

**Methods:** Participants were caregivers of HIV-positive children recruited from Shalom Delhi's Palliative Care Program for persons living with HIV/AIDS. A mixed quantitative and qualitative interview tool was used. Participants were asked to come to Shalom Delhi's outpatient clinic, where the primary investigator provided a medical check-up for the positive child and administered the questionnaire.

**Results:** Forty-seven caregivers of positive children were interviewed. The ages of the children under investigation ranged from 3 to 16 years. 47% ( $n = 22$ ) of children lost their fathers, while 6% ( $n = 3$ ) lost their mothers. The median family income was Rs. 6000 per month. 38% ( $n = 15$ ) of the positive children knew their status. Those caregivers who did not disclose the child's status to them ( $n = 32$ ) feared that the child either would lose respect for the parents (55%) or lose their self-worth (42%) if the status were to be disclosed. Furthermore, when caregivers were asked (via an open-ended question) about worries for the child, 98% of caregivers expressed worry about the child's future, 68% ( $n = 32$ ) expressed concern about child support when the caregiver(s) die(s), 47% ( $n = 22$ ) expressed concern about the child's future marriage prospects, and 19% ( $n = 9$ ) expressed concern about the child's future health.

**Conclusion:** Given the complexities of HIV in terms of not only health but also stigma and feared discrimination, HIV-positive children and their caregivers face tremendous barriers to quality of life. Palliative care teams must address their complicated needs, paying particular attention to issues of status disclosure and worries about the child's future.

**Key words:** Disclosure, HIV, Paediatric, Palliative care, Worries

#### OD-09

### SURVEY ON THE ATTITUDE AND KNOWLEDGE OF POSTGRADUATE DOCTORS ABOUT END-OF-LIFE ISSUES IN INTENSIVE CARE IN A TERTIARY REFERRAL HOSPITAL

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**Background:** The mission of intensive care includes avoidance of inappropriate use of aggressive interventions. The training in intensive care includes skills of palliative and end-of-life (EoLC) care, and this requires the same high level of knowledge and competence as other aspects of intensive care. Effective EoLC is considered as one of the top priorities for the Indian Intensive care units and EoLC was the focused theme of the Indian Society of Critical Care and Palliative Care Society of India for the year 2014. Literature suggests that intensive care residents in the US are only moderately comfortable in dealing with this important topic. There is very limited information available on the attitudes of intensive care residents towards EoLC, in India.

**Methods:** We decided to conduct a postal survey on the attitudes of our intensive care residents towards end of life, the training they receive in this field and the skills they acquire during their placement in intensive care. Residents from all the intensive care units at Amrita Institute of Medical Sciences, Kochi, who have completed at least one month's placement in intensive care were included. The questions are based on a 5 point Likert scale. A response rate of 50% or more is considered an acceptable response rate and a reflection of the study population. Ethics committee approval will be obtained from the hospital ethical committee.

**Results:** The results will be discussed later.

**Conclusion:** The conclusion will be discussed later.

**Key words:** Attitudes, End of life, Intensive care

#### OD-10

### CHALLENGES IN MANAGING MULTIPLE DIAGNOSIS AND SYMPTOMS AMONG PEOPLE LIVING WITH HIV IN AN HIV PALLIATIVE CARE CENTRE IN A RESOURCE-POOR SETTING

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**Background:** People living with HIV, in the terminal or acutely symptomatic stage often have multiple opportunistic infections. They also suffer from multiple major symptoms,

either as a result of the infection or as a side effect of their medication. Managing these patients in a resource-poor setting is very challenging.

**Description:** This paper will describe the challenges in managing multiple diagnoses and symptoms among people living with HIV who were admitted to a care centre. This centre is run in Koppal, Karnataka, by Samraksha. Samraksha has been providing centre-based palliative care services for people living with HIV in Karnataka since 1997.

In a period of one year, 318 clients were admitted to the care centre. All of them had three or more major symptoms, around 65% had two or more opportunistic infections.

**Challenges:** Challenges include the need to prioritize and manage the order of intervention for the different symptoms, and also the need to manage presumptive treatment in the absence of clear evidence from medical investigations. Communicating decisions regarding treatment to family members and gaining consent is also important. Sometimes, surgical intervention is necessary. But there is denial or delay in surgery in tertiary care services, which impede treatment and care.

**Conclusion:** Managing multiple diagnoses and symptoms among patients living with HIV in resource-poor settings is very challenging. A multi-disciplinary team drawn from local human resources, and good linkages with diagnostic services and tertiary care services are necessary to manage them.

**Key words:** HIV palliative care, Multiple diagnoses, Multiple symptoms, Resource-poor settings

#### OD-11

### ESTIMATION OF VITAMIN D LEVEL IN CHILDREN WITH CEREBRAL PALSY ATTENDING THE PALLIATIVE CARE CLINIC IN A TERTIARY CARE CENTRE

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**Background:** Vitamin D is a fat-soluble vitamin which is needed for our body. Its biochemical action includes absorption of calcium and phosphorus from the gut. It helps in normal functioning of our muscles, mineralization of bones and teeth. Thus, it is much needed for the normal growth and development of children. The deficiency of Vitamin D will lead to developmental delay, growth retardation, weakness, bone pains, fractures, and dental problems. The clinical manifestation of deficiency of Vitamin D is rickets in growing children and osteomalacia in adults. Hence, its deficiency will add on to the morbidity of children with cerebral palsy. The major source

of Vitamin D is synthesis in skin by sunlight, followed by dietary sources. Children with cerebral palsy are inadequately exposed to sunlight. Their dietary habits are also inadequate. In addition, many of them are taking anti-convulsant drugs, which by themselves cause Vitamin D deficiency.

**Objective:** Primary: To study the prevalence and magnitude of Vitamin D deficiency among children with cerebral palsy. Secondary: To study protein energy malnutrition and stunting among these children.

**Design:** Hospital-based cross-sectional study

**Setting:** Pain and palliative care clinic in a tertiary care centre (Government Medical College, Trivandrum). The clinic is conducted jointly by the Department of Paediatrics and the Department of Paediatric Neurology in association with Pallium India.

**Methodology:** Ethical clearance was obtained before the start of the study. Informed consent was obtained from the care giver. Confidentiality was maintained and there was no financial burden on the child. All children with cerebral palsy attending the palliative care clinic were included in the study. They were examined clinically in detail including growth, protein energy malnutrition and stunting. Vitamin D estimation was done in an accredited laboratory. The results will be compared with accepted standardised reference values.

**Analysis:** The results will be entered in Excel and the analysis will be done using SPSS by an appropriate statistical method. The results will be obtained by the first week of December.

**Key words:** Cerebral palsy, Vitamin D

#### OD-12

### AUDIT OF PAIN INCIDENCE AND IMPACT ON QUALITY OF LIFE FOR LEPROSY-AFFECTED PATIENTS TREATED AT GREEN PASTURES HOSPITAL AND REHABILITATION CENTRE, POKHARA, NEPAL

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**Background:** Neuropathic pain (NP) in leprosy is well recognised, particularly affecting patients with multibacillary subtype (MB) and persisting up to 10 years after Multidrug Therapy (MDT). Few studies have addressed total pain experience in LAP. GPHRC treats LAP and those with spinal cord injuries (SCI) and this audit was undertaken to assess their pain management needs. Results for the subgroup of LAP are presented.

**Methods:** Presence, frequency, severity and type of pain experienced by 95 LAP was surveyed with a questionnaire

combining “AMFES” developed for leprosy pain research, the International SCI pain questionnaire, and the DN4 for NP. Clinical accuracy of NP diagnosis was compared with DN4 outcomes (taken as gold standard). Impact of pain on sleep, mood and daily activities was reviewed. Results were compared between leprosy subtypes and MDT status. Analysis utilized SPSS v20.

**Results:** 79/95 (83%) of all patients had experienced pain in the previous week, with 27/79 (34%) reporting mild, 22/79 (28%) moderate and 30/79 (38%) severe pain. 38/79 (48%) reported one pain, 28/79 (35%) two and 13/79 (17%) three or more pains. 52/79 (66%) had neuropathic pain on DN4. A total of 136 types of pain were reported and 69 (51%) of these were neuropathic. 47/79 (59%), 61/79 (77%) and 64/79 (81%) reported a moderate or severe impact of pain on sleep, mood and activities of daily living respectively. This was higher in those with NP, although the difference was not statistically significant. Leprosy type and MDT status did not affect pain experience. Clinical diagnosis of NP against DN4 score revealed: sensitivity 88%; specificity 48%.

**Conclusion:** In GPHRC, LAP pain occurs more frequently than previously reported, with similar levels of pain and severity as cancer patients and a major impact on QoL. Whilst most patients with NP are identified clinically it tends to be over-diagnosed. A follow up programme of education in pain management is being developed.

**Key words:** Leprosy, Neuropathic pain, Pain incidence, Quality of life

#### OD-13

### HEALING AND MOVING ON: ADDRESSING THE TOTAL PAIN OF HIV-POSITIVE WIDOWS

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**Background:** The current treatment modalities in HIV do not give women, who lose their spouses, time to grieve. Samraksha, an organisation working in HIV palliative care in rural North Karnataka found that immediately upon the death of their spouse due to HIV, the widows were drawn into the urgent process of testing and treatment most of the time. Samraksha’s palliative care team found that the deep anger at being infected and at the drastic change of roles and lifestyle was only exacerbated as time went on, by the social exclusion imposed by widowhood in rural Karnataka. Their physical condition, their shock and distress at being

HIV positive, their grief at the loss of their spouse along with the changes in their role and social status left them in a state of Total Pain.

**Description:** Samraksha developed an 18-month programme with 70 HIV-positive women, who were widowed, to facilitate the process of healing. Using multiple methodologies, the programme focussed on creating safe places for the expression of psychological and emotional pain. Relief of physical symptoms simultaneously received attention. Facilitating life competence through strengthening social and economic skills dealt with the overwhelming pain experienced by the women through widowhood-related issues.

**Findings:** The analysis of the programme showed that Total Pain marred the motivation and ability of the participants to benefit from the diverse resources available to HIV-positive women. Also, the findings showed a marked progress on an instrument to measure healing. The paper will present the core interventions and findings of the 18-month process and one illustrative case study.

**Conclusion:** A group intervention with a grieving population facing Total Pain, with diverse activities to promote healing can provide significant benefit.

**Key words:** Healing, HIV-positive widows, Total pain

#### OD-14

### IMPACT OF AN EDUCATIONAL PROGRAMME ON PARAPLEGIC (COMPLETE SPINAL CORD INJURY) PATIENTS

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**Background:** Spinal injury is a low-incidence but high-cost disability. Around 70% of cases are between 18 and 30 years of age, of whom 81.6% are male. Depending on the location and the extent of the injury, paralysis may be paraplegic or quadriplegic.

**Objective:** To investigate patient knowledge about spinal cord injury, and to evaluate the impact of an educational intervention.

**Setting:** Alpha Palliative Care Hospice.

**Methods:** From May 2012 to April 2015, 42 complete spinal injury patient (level below T2) were interviewed. After the interview, each patient was administered a structured educational program and again interviewed after three months. The pre- and post-intervention responses were compared using Chi-square test.

**Results:** After the intervention, there was a significant improvement in patient knowledge about:

1. The importance regular exercise to avoid contracture of muscles and soft tissue
2. The frequency and duration of therapy necessary to improve functional abilities
3. The importance of following up regularly with a neurologist and physiotherapist
4. Preventing and managing bed sores
5. Managing wheelchair and improving quality of life.

**Conclusion:** The impact of an educational intervention on paraplegic patients, with the short duration, is inadequate. A single-session educational programme can significantly improve the quality of life of the patient but regular education may give better results.

### OD-15 ACCOMPANYING GRIEVING ADOLESCENT CARERS IN HIV

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**Background:** Adolescent carers of parents and siblings living with HIV carry a great deal of unresolved grief and the continuing fear of loss of one or both parents and siblings. As this grief is embedded in family secrets and silence about HIV within the family, it is suppressed.

**Description:** Samraksha, an organisation working with HIV Palliative Care in rural North Karnataka, worked for 18 months with a group of 25 adolescent girls between 13 and 18 who had lost one or both parents to HIV. They had been or were carers, 8 of them were living with HIV themselves. The intervention consisted of accompaniment of these girls over a year through group activities, excursions, reflective spaces, creation of peer support networks, art experiential, and one-to-one conversations.

**Findings:** The intervention created safe places for the expression of past and anticipated loss. It also helped the release of fears about health, death and dying issues of their own and that of their family members. The peer support network provided relief from the extremely isolating experience of being carers in a secretive environment. The authors will present the grief accompaniment process and the impact on the participants at the end of 18 months.

**Conclusion:** The challenges faced from family environments of fear and secrecy in HIV care, and the trauma of unexpressed grief in adolescence require sensitive accompaniment and support through a range of diverse methodologies.

**Key words:** Accompaniment, Adolescent girls, Carers, Grief, HIV

### OD-16 THE CAREGIVER'S DIFFICULTY RATING SCALE: DEVELOPMENT AND INITIAL VALIDATION OF AN INSTRUMENT TO ASSESS CARE-GIVING BURDEN ON FAMILY CAREGIVERS OF CANCER PATIENTS

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**Background:** Cancer affects not only the patient but the entire family as providing care may result in burdensome feelings for caregivers. For holistic care of patient and family, caregiving difficulties need to be assessed but little is done to develop cancer-specific measuring instruments in the Indian context. This paper presents the development and the initial validation of a caregiver's burden assessment scale to empirically measure caregiving burden on family caregivers of adult cancer patients.

**Methods:** A pool of 108 items were initially prepared in English after case-interviews and reviewing burden assessment scales from gerontology, psychiatry and oncology for face validity. These items were presented to experts for content validity and items with 100% agreement were retained leaving 54 items. Pre-testing of final items dropped four more. These were translated in Hindi using forward-backward translation policy and three translated versions administered to a sample of 30 respondents for reliability analysis. Final scale was administered to 100 caregivers of head and neck cancer patients both from IPD and OPD for further internal consistency and item-scale statistics. For construct validity know-group comparison was made using EORTC QOL instrument and hypotheses were prepared on medical and demographic characteristics of caregiver-patients dyads.

**Results:** High correlation among three translated versions ( $r > 0.76$ ,  $P < 0.01$ ), Cronbach's alpha (0.948), and split-half coefficient (0.965) suggested translation was reliable and scale-consistent. Caregiving burden had significant negative correlation with global quality of life of patients (-0.514), supporting the existing theory base. Eight other hypotheses for construct validity were confirmed.

**Conclusion:** Final version of CDRS had 50 items under four dimensions, viz. physical burden, emotional distress, social relationship strain and financial hardships. Though the scale possesses adequate validity, reliability and internal consistency, it requires further work on convergent and divergent validity, and testing sensitivity to change. These are underway.

**Key words:** Burden, Cancer, Caregiver, Scale, Validity

**OD-17****A SMARTPHONE APPLICATION TO PROMOTE AWARENESS AND PARTICIPATION OF VOLUNTEERS FOR A HOSPICE IN UTTARAKHAND, INDIA****Aditi Chaturvedi, Dewan AK<sup>1,2</sup>**

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**Introduction:** WhatsApp Messenger is a cross-platform mobile messaging app which allows users to exchange messages by mobiles with internet facility. WhatsApp users can create groups and send each other unlimited images, video and audio media messages. A study was planned to assess the utilization of this app for spreading awareness about palliative care and for communicating with volunteers about the need to provide help for palliative care patients. The study also assessed users' response rate.

**Methods:** A Ganga Prem Hospice WhatsApp group was created and all the volunteers who had smartphones and were willing to offer help to the hospice were included in the group. The group included medical and non-medical volunteers. Material shared by the group included patient-related stories, particularly those patients needing volunteer assistance, experience of volunteering, local and national palliative care developments, volunteer training programmes organized by Ganga Prem Hospice, and motivational quotes.

**Results:** As on October 27, 2015, Ganga Prem Hospice WhatsApp group has 51 participants. There are 15 doctors, 2 nurses and 36 NMSA (non-medical socially active) volunteers. Examples of patient issues addressed through Ganga Prem Hospice WhatsApp group include:

1. Arranging funds for part-time assistants (maids) for bed-ridden patients.
2. Arranging visits by NMSA volunteers to patients.
3. Arranging meals for patients who had difficulty cooking.
4. Arranging devotional and meditation CDs for patients as requested.
5. Arranging funds for basic routine investigations for patients.
6. Correcting myths related to cancer and palliative care. Some non-medical users occasionally posted some magical healing techniques for cancer to the group. The doctors in the group would discuss and clarify the myths.
7. Arranging treatments from an aromatherapist and acupuncture therapist for patients.
8. Arranging help of translators (English-Hindi) for GPH volunteer doctors from abroad.

9. Arranging equipment like wheelchairs for patients.
10. Follow up and review of patients after home care visits.

438 messages were shared on the group between September and October 2015, out of which 179 (40.86%) messages were related to palliative care. Help was asked in ten messages and the response and actual help offered was 100%.

**Conclusion:** WhatsApp may be considered as a way to spread awareness and receive volunteer help for hospice work.

**Limitation:** Volunteers without smartphones could not be included in the group.

**OD-18****MIXED METHOD EVALUATION OF A PALLIATIVE CARE PROJECT IN RURAL NORTH INDIA****Daniel Munday, Erna Haraldsdottir<sup>1</sup>, Manju Manak<sup>2</sup>, Ann Thyle<sup>3</sup>, Cathy Ratcliff<sup>4</sup>**

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**Background:** Since 2009, Emmanuel Hospitals Association (EHA) has been developing a community model of palliative care (PC), appropriate to rural north India. This is based on a needs assessment, which identified that dying patients are frequently sequestered in their homes, receiving little care from families impoverished by expensive curative treatment and lacking the knowledge and skills to care. Outreach teams deliver awareness building in villages, identify patients and care for them in their homes. Hospital admission and OPD are available as required. EMMSI, a UK agency, funded the programme in five hospitals since 2013 and commissioned this independent evaluation.

**Methods:** Mixed method rapid realist evaluation was undertaken with data collected from documents and activity records; field observation of services and 44 in-depth interviews with EHA leaders, hospital staff, patients, carers and community members. All teams were assessed against Pallium India PC Standards and overall programme approach through WHO Public Health for PC.

**Results:** Each team followed the EHA model, with local contextual modifications. Most care was home-based mainly to cancer patients plus a few with HIV, paraplegia and other non-communicable diseases. Staff who had been carefully selected displayed excellent commitment and vision; most had completed the IAPC introductory course. All teams achieved most Pallium markers apart from morphine utilization; despite great effort only 2/5 had secured morphine licenses. The programme demonstrated compliance with WHO principles.



Remarkable synergy was emerging between PC and community health, supporting the community-based approach. Hospitals were exploring “social enterprise” approaches to achieving sustainability, e.g. small profits from surgical services utilized to fund PC.

**Conclusion:** This service exemplifies a locally appropriate, evidence-based, iterative approach to PC development. Further multidisciplinary education and targeted research could enhance the services and the model could be extended to similar sites. The overall approach has wider applicability for PC service development.

**Key words:** Community health, Mixed methods study, Palliative care, Service evaluation

### OD-19

#### HEALTH NEEDS AND EXPERIENCES OF VULNERABLE PEOPLE INVOLVED IN NATURAL DISASTERS IN LOW- AND MIDDLE-INCOME COUNTRIES: A SCOPING LITERATURE REVIEW

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**Background:** The needs of vulnerable people (with advanced chronic illness, frail elderly and people with severe disability) experiencing natural disasters and possibly requiring palliative care have not often been considered. Following Hurricane Katrina in New Orleans (2005) researchers began considering their needs. As more people in low/middle-income countries (LMIC) suffer from advanced non-communicable disease and global warming leads to an increase in incidence and seriousness of natural disasters, these issues will become increasingly important. This paper explores the evidence of needs and experiences of vulnerable people affected by natural disasters in LMIC.

**Methods:** Scoping literature review utilizing: Medline, Cinahl, Web of Science, combining search terms: natural disasters, humanitarian disasters, palliative care, older adults, elderly, chronic disease, disability, disabled, vulnerable adult. Inclusion: research studies following earthquakes, floods, cyclones, tsunamis or landslides in LMIC exploring needs or experiences of vulnerable adults and children. Exclusions: editorials, opinion and discussion papers. Narrative analysis was undertaken.

**Results:** 1820 titles identified, 389 abstracts and 39 papers read following exclusions. 25 papers meeting inclusion criteria retained for analysis. 17/25(68%) had been published in the last 10 years. Study context was: earthquakes (16), cyclones (2), tsunamis (2), floods (1) and mudslides (1) in Asian and Latin American countries. No study mentioned palliative care or related to vulnerable children. The commonest focus

was mental health in older people. Epidemiological studies reported that vulnerable people were more likely to die in disasters. Several studies reported chronic disease management as a common health care need encountered post-disaster, but health workers and relief teams were frequently unprepared.

**Conclusion:** There is increasing interest in the needs of vulnerable people in natural disasters in LMIC. Aid agencies are being encouraged to provide for the needs of people with chronic illness. Specific studies exploring the needs for palliative care in such situations are required.

**Key words:** Health care needs, Humanitarian emergencies, Low/middle income countries, Natural disasters, Vulnerable populations

### OD-20

#### HOME CARE FOR TERMINAL ILL CANCER PATIENTS: A SERVICE WHICH IS BEYOND THE REACH OF TERTIARY CARE HOSPITAL, AN OBSERVATIONAL STUDY

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**Background:** Home is the place where majority of people want to be when they are in terminal stages, close to their near ones in familiar surroundings especially for cancer patients in incurable stage and the end of life approaches. In order to improve symptom control and imbibe good quality of life, the home care team enables patients to stay at home, and this reduce hospital admissions. JIPMER Palliative Home care team consist of one specialist doctor, one resident doctor, one social worker, one palliative care nurse and three nursing trainees along with local village volunteers.

**Methods:** Total 1780 new cases were registered under palliative care service, RCC, JIPMER in the year 2015, out of which 108 cases were registered under home care and prospectively studied to assess the impact of specialist home-based services using Functional Assessment of Cancer Therapy FACT-G questionnaire. The team had to travel 1550 km per visit and the minimum frequency was twice a month.

**Results:** Out of the 1780 registered cases, only 108 patients received home-based palliative care. Out of which, 70% patients were taken care at home, 15% patients required hospice referral and old age home referral and 15% patients needed respite admission at RCC. All patients who received

specialist home care had adequate relief from physical symptoms ( $P < 0.001$ ). Home care team liaised with the community doctor, so that the continuity of care was maintained. They were contacted during the home visit personally or via telephone. 75% patients received out-of-hours care (OOH) through liaising with community doctor; 15% received home-based bereavement care and only 40% had good bereavement outcomes.

**Conclusion:** Specialist home-based palliative care could only focus on improving symptom control, but other health-related communication social and psychosocial support was beyond reach of our palliative care team. Effective palliative care services require a dedicated home care team with integration of the existing health system at all levels of care, especially community and home-based care. In this way, home based care for dying patients can be promoted with appropriate and early hospice referral, and avoiding unnecessary hospitalization.

**Key words:** Bereavement care, Cancer, Community care, Home care

#### OD-21

### IN THE MIDST OF SUFFERING: A LITERATURE REVIEW OF DOCTORS' ENCOUNTERS WITH THE SUFFERING OF THEIR PATIENTS WHO ARE APPROACHING THE END OF LIFE

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**Background:** Encounters with suffering are a frequent occurrence in palliative care practice, for all palliative care practitioners. However, there has been little discussion of how doctors recognise and respond to suffering other than in the context of refractory suffering at the end of life. Suffering may occur at any time in the illness experience and challenges health practitioners. What is the experience of doctors who are exposed to the suffering of dying patients? This paper will present the outcomes of a systematic literature review of doctors' experiences when caring for suffering patients nearing the end of life. The aim of the review is to develop a conceptual schema to underpin subsequent narrative analysis of 18 interviews undertaken with doctors working in India and Australia about their experiences in caring for suffering patients at the end of life.

**Method:** A comprehensive systematic review of experiences, impact and attitudes of doctors, including medical students, who care for patients at the end of life was conducted using electronic search of Medline, CINAHL, and PsycINFO

databases from 1960 to 2015, supported by hand-searching and review of reference lists of included studies. Both qualitative and quantitative studies are included in the review and a quality metric was constructed for both qualitative and quantitative papers, derived from a number of approaches suggested in the literature (Mays *et al.*, 2005, Spencer *et al.*, 2003, CASP, 2010, Goldsmith *et al.*, 2007).

**Results:** From over 400 articles identified in the citation and other searches, an initial sample of 21 papers were eligible for quality review, of which the final sample will be selected for data extraction and detailed review. Results of the literature review and data synthesis and the derived conceptual schema will be presented.

**Key words:** Attitudes of health personnel, Palliative/terminal care, Physicians, Psychological, Stress, Suffering

#### OD-22

### TRAINING ISSUES IN HOLISTIC APPROACH TO PALLIATIVE CARE IN ADVANCED DEMENTIA

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Advanced dementia (AD) is a terminal illness and its clinical course is well characterized. Management of advanced dementia specially in home/hospice setting requires a holistic approach so that the journey taken by the patient, family and the care-provider is of a smooth nature which promotes harmony and balance in the terminal phase of a person's illness. Holistic approach towards dementia has both pharmacological as well as non-pharmacological components. Because currently available therapies cannot reverse the pathological processes of AD, the primary objective of non-pharmacological interventions is to preserve cognitive, behavioural and functional ability, minimize behavioural disturbances, and slow disease progression.

In striving for a holistic approach to care and a healthy state one needs a balance and harmony in all aspects of the person's lifephysical, social, emotional, cognitive and spiritual. It is equally important to remember that providing palliative care at home/hospice is centred on the family unit. The dementia trajectory frequently means family members have been involved over a long period of time and provided much of the care. The constant exposure by family members to the person's declining cognitive state may be expressed as anticipatory grief or pre-death (before the actual physical death of the person occurs). Recognizing how families are feeling and coping with their loss and grief has a direct impact on the person with dementia, which often contributes to their anxiety, depression, wandering and other displays of behaviour. Addressing the

physical, intellectual, emotional and spiritual needs, within the cultural context of the family unit, thus is an equally important aspect of care of such patients.

**Results:** Responses emphasized the need for improved knowledge and skills, and clearer policy. Structured training of the care provider in the holistic approach after assessing their training needs, specially in home setting is of paramount importance and is often overlooked. Such training is complex and must involve effective communication and soft skills, knowledge about dementia, management of behavioural challenges and other symptoms.

### OD-23

#### AN OVERVIEW OF PAEDIATRIC PALLIATIVE CARE IN THE UNITED STATES

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**Background:** Paediatric palliative care is distinct in many regards from adult palliative care. Far fewer children in the United States die compared to adults. The primary diagnoses for palliative care referral are neuromuscular and genetic/congenital rather than oncologic, and often palliative care is provided over a longer period of time. There is also a stronger presumption toward aggressive treatment for the simple reason that the patient might “still have his whole life ahead of him.” While palliative care in general is a relatively new specialty in the United States, paediatric palliative care is still in its infancy and seeking to establish itself within the American health care system.

**Methods/Results:** This presentation will review national data on the role and growth of paediatric palliative care in the United States, with reference to training opportunities, institutional programmes, regulatory issues (including the impact of the Affordable Care Act, or “Obamacare”), and advocacy. Specifically, barriers to hospice enrolment, frequent misperceptions among paediatric clinicians, and the impact of increasing rates of opioid addiction will be addressed. In addition, it will describe the implementation of a paediatric palliative care team at a rural academic medical centre, including collaboration with other services to form a multidisciplinary team. There will be an opportunity to explore possible collaborations between India and the United States, both clinically as well as educationally through reference to the Annual Assembly of the American Academy of Hospice and Palliative Medicine, which occurs the month after the IAPC International Conference.

**Conclusion:** Paediatric palliative care in the United States is an evolving specialty facing unique opportunities and challenges. Further dialogue with other paediatric palliative care specialists will only serve to enhance the field and further our work together.

**Key words:** Palliative care, Paediatrics, United States

### OD-24

#### PREVENTION OF HIP FRACTURE IN ELDERLY PEOPLE THROUGH USE OF AN EXTERNAL HIP PROTECTOR

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**Background:** Hip fractures are a major cause of disability, functional impairment and death in elderly. These are associated with an appreciable mortality/morbidity and are a serious threat to independence. Most are related to both falls and osteoporosis. Fracture treatment is expensive, and rehabilitation is not always successful. Continuous usages of hip protectors can be a preventive measure towards avoiding a fracture. Hip protectors have been advocated as safe and non-invasive devices capable of reducing hip fracture risk. These are believed to be effective as they absorb or diffuse energy rather than relying on bone strength for resisting fractures during fall(s).

**Objective:** To evaluate compliance rate and confidence level for regular use of hip protectors amongst elderly Indian population.

**Study design:** Hip protector study was designed as an observational prospective study.

**Methods:** Total number of participants enrolled were 52 in hospital and 75 in senior citizens' society. The target population consisted of male and female subjects, above 65 years of age with or without hip fracture. All participants were required to possess high risk of fall, therefore, resulting in potential hip fractures. The follow-up duration of this device was 3 months. Patients were enrolled in the geriatric ward, orthopaedic outpatient department of All India Institute of Medical Sciences, New Delhi and Ramprastha Senior Citizens Association, Ramprastha, Ghaziabad.

**Results:** 73% compliance was observed within hospital and 97% in senior citizens' society. Comfort level was observed to be 90% in study group and confidence level almost 100%.

**Conclusions:** Hip protector seems to be an effective device that can reduce chances of hip fractures and injuries within the elderly. The outcome provides health professionals

and caregivers greater awareness of strategies to improve compliance through use of hip protector.

**OD-25****THE IMPACT OF PAIN ON QUALITY OF LIFE OF PATIENTS WITH ADVANCED CANCER**

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**Introduction:** Pain due to cancer is one of the most common symptoms which may be manifested non-predictably any time during the course of the illness. It invariably affects the quality of life (QOL) of patients irrespective of the stage of disease.

**Objective:** The objective of the study was to identify the impact of pain intensity on multiple domains of QOL among cancer pain patients in pain due to cancer.

**Methods:** This study was a part of larger research study conducted at the Department of Onco-Anaesthesia and Palliative Medicine at Dr B.R.A. Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi. It was a prospective study enrolling newly-registered adult subjects with histologically documented diagnosis of a cancer-related pain. Complete history of pain and its treatment were recorded as per the "Pain Form" developed and used at our institute. QOL of patients suffering from cancer pain was observed with the Hindi version of World Health Organisation-Quality of Life instrument (i.e. WHOQOL-BREF). Statistical analyses were done using STATA version 14. Spearman rank correlation coefficient was calculated to identify the association between the pain correlates and quality of life domains.

**Results:** Cancer pain was significantly negatively correlated ( $p < 0.05$ ) with physical and environmental domains of QOL. Physical domain includes items related to daily activities, pain, sleep, energy, work capacity etc. Environmental domain encompasses aspects like transport, financial resources, physical safety, opportunities for leisure activities etc. However, psychological domain and personal relationships were not significantly correlated with pain intensity.

**Conclusion:** It is important to acknowledge that environmental factors and physical interferences have a detrimental effect on overall QOL. These findings highlight the need for acknowledging environmental factors as well while providing patient-centred care.

**Key words:** Advanced cancer, Cancer pain, Quality of life

**OD-26****EVALUATION OF "TOTAL PAIN" IN CANCER PATIENTS IN INDIAN CONTEXT: A PILOT STUDY**

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**Introduction:** Dame Cicely Saunders first proposed the concept of total pain in 1967 to describe the multidimensional nature of pain in cancer patients. The term "total pain" because physical, psychological, social and spiritual pains affect a patient's life. Since then many instruments have been developed to assess effect of pain in cancer patients but none of the instrument includes all components of total pain on patient's life. At present there is no universally accepted tool to assess "total pain" due to cancer.

**Objective:** To develop an instrument to assess all the components of "total pain" in cancer patients in Indian set-up.

**Methods:** The development of the Total Pain Scale (TPS) to evaluate total pain in cancer patients was carried out at pain and palliative care clinic in Dr. BRA, IRCH All India Institute of Medical Science New Delhi, India. TPS was developed via extensive literature review and by consultation with panel of pain and palliative care experts. For standardisation, pilot study was performed in 100 patients and results were analysed to evaluate both reliability and validity.

**Results:** The reliability coefficient within the components of total pain was satisfactory (i.e.  $\alpha > 0.74$ ). Physical aspect contributed nearly 40% towards total pain, while non-physical factors like social, psychological and spiritual contributed approximately 60%.

**Conclusion:** All the factors of total pain (i.e. physical pain, social pain, spiritual pain and psychological pain) should be considered while treating cancer pain in palliative care patients.

**Key words:** Cancer pain, Total pain

**OD-27****LOW AWARENESS OF STUDENTS OF MEDICAL AND ALLIED PROFESSIONALS IN INDIA ABOUT THE BASICS OF PALLIATIVE CARE**

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**Objectives:** To assess the awareness of basics of palliative care among final year students of medical and allied

professions. To infer their readiness to accept palliative care principles based on their feedback on a two-day workshop in basics of palliative care.

**Background:** The World Health Organization (WHO) prioritises health policy, professional and community level education and drug availability for advancing palliative care services in resource-constrained settings. Trivandrum Institute of Palliative Sciences (TIPS), a WHO Collaborating Centre for Training and Policy on Access to Pain Relief, has developed undergraduate medical and nursing curricula in palliative care, in 2014. To facilitate the roll out the curricula, workshops were conducted in various medical schools in different parts of India.

**Methods:** This study looks at awareness about basics of palliative care as noted from pre- and post-test responses in student workshops in two medical colleges from Kerala, one from Pondicherry and one from Kanpur (student profile: medical 703 medical; 129 nursing; 32 physiotherapy). A synthesis of the potential acceptance of palliative care principles was attempted from their feedback comments.

**Results:** At the pre-test level, only 22.9% students were fully aware of select basic principles of palliative care. Students from Kerala had better awareness regarding palliative care (38.9%) as opposed to other parts of India (7.5%). Students with personal experiences of chronic pain or distress in loved ones seemed to be more ready to accept the palliative care approach. Some reported having observed pain prescriptions very different from the WHO pain management strategy.

**Conclusion:** Majority of medical students at the threshold of graduation were not aware of the basics of palliative care. Awareness was better in Kerala probably due to the more favourable policy environment. Many students are likely to have observed irrational pain management practices during their clinical postings.

#### OD-28

### A STUDY ON THE SERVICES DONE BY PALLIATIVE CARE TEAM IN OUT-OF-HOURS SETTING IN KOZHIKODE, KERALA

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**Objective:** This study reviews the services provided by palliative care team in out-of-hours setting in Kozhikode, Kerala.

**Background:** The out-of-hours service was launched in Kozhikode city, Kerala in June 2010. The unit has a staff nurse and a supervising doctor. A helpline is active throughout the

night and emergency calls from registered patients are attended. After assessing the situation, the team visits the patient at home and provides care. The case histories of all the patients are recorded in the case files with the team. This helps them to refer the case, while attending the call. A doctor is available at night to seek advice over the phone and to visit patients if needed.

**Methodology:** A record-based cross-sectional descriptive study was done between September and December 2015. It covered all patients seeking care from out-of-hours service team. The aim was to assess the reasons for emergency call, how it was managed and interventions by the out-of-hours service team, over the last four years.

Information on the study variables has been collected from the case records maintained in Institute of Palliative Medicine (IPM) after necessary administrative permissions to access records. Data collection is being done by single investigator using data extraction sheet from the emergency home care records of palliative care patients. The proforma has the questions pertaining to identification and demographic details of the subject, diagnosis and reason for the referral and the interventions. Data is being entered using Epi Data v3.1.

**Result:** The analysis of the data obtained will be done using SPSS v19.0. Results will be expressed in descriptive and inferential statistics.

#### OD-29

### REVIEW OF ADMISSIONS TO ICU IN A CANCER CENTRE: SHOULD PATIENTS SUFFERING FROM TERMINAL CANCER BE ADMITTED TO ICU?

**Anjna Puri Surath**

Palliative Care Physician

**Objective:** To analyse the pattern of admissions to ICU in a dedicated cancer centre with a view to identify terminally ill who are likely to die in ICU.

**Methods:** The case records of all patients admitted to ICU between January 1, 2014 and December 31, 2014 were reviewed for diagnosis at admission, history of background treatment and recent management, quality of life in the previous 3 months and condition at the time of admission. The patient's status at discharge or the cause of death were noted.

**Results:** Medical records of the 433 patients who were admitted to or were shifted from wards to ICU were analysed. Of these 250 patients were found to have terminal cancer or relapsed cancer without further options for definite treatment. After-working-hours admissions to ICU numbered 231 whereas only 12 patients were admitted to ICU from OPD. 190 patients were shifted from wards. 215 deaths took place in ICU and 90 patients went out in a moribund state.

**Conclusion:** Almost 50% mortality in any ICU is unacceptable and leads to stress among the staff. A proper counselling at the end of definite care for cancer and integration of palliative care with primary treatment will help to reduce the admissions to and mortality in ICU.

**OD-30  
CARE GIVERS' PERSPECTIVES ON END-OF-LIFE AT HOME**

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**Aims:** To study the impact of home care on care givers of patients with advanced cancer, receiving end-of-life care at home.

**Study Design:** This was a qualitative study. Family members of patients receiving end-of-life care (EOLC) were interviewed using a semi-structured format. All the interviews were recorded and transcribed from Kannada or Hindi to English. Theme saturation was achieved within the first 7 interviews. The inclusion criteria for the study were: Patient and family should have received a minimum of four home care visits. Interviews held with only those patients who had active care givers at home.

**Analysis:** Transcribed notes were reviewed. The data from each interview was analysed individually, then pooled prior to reviewing for the emergence of specific themes. Further discussion of these themes with the wider multidisciplinary team contributed to data synthesis and interpretation.

**Results:** Originally, care givers of 15 patients were interviewed. However, three were deemed unsuitable as a result of either poor communication or lack of comprehension. Findings from the remaining 12 were incorporated into this study.

*Perceived positive findings*

- Preference for care at home towards the end.
- Achieving comfort at home.
- Cost effectiveness. Improved knowledge about patient care.
- Individualized attention.
- Provision of medicines at home.
- Easier access to professional medical help.
- Psychological and physical support reducing carer's own stress.

*Areas for improvement*

- More frequent visits/emergency care when needed.
- Provision for death certificate at home.
- Continuity of morphine supply at home.
- Difficulty maintaining anonymity in community setting.

**Discussion:** Input from the home care team was felt to enable and empower the care givers to be better prepared and engaged in looking after their loved ones at home.

**Key words:** End-of-life, Home care, Hospice

**OD-31  
PSYCHO-SPIRITUAL ISSUES IN PATIENTS ADMITTED FOR HOSPICE CARE**

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**Background:** In cancer patients, pain and other distressing symptoms are often the main reason requiring in-patient admission to a Hospice for cancer patients, however, these physical problems are usually seen within the context of a more complex collection of psycho-spiritual concerns.

**Objective:** To elicit and document these issues, working through experienced counsellors who are an integral part of the multi-disciplinary clinical team.

**Methods:** This was a retrospective study, based on a standardised pro-forma that has been used in-house for the past 3 years. Notes from 25 in-patients, randomly selected from a two-year period, have been analysed for common themes. Patients had a variety of malignancies and their ages ranged from 15 to 75 years (mean: 44, median: 47). Religions: Hindu - 20; Christian - 4; Muslim: 1.

**Results:** 22 different issues were noted and thematic saturation reached within the first 10. These have been loosely collated into five inter-related main groups; three with negative connotations and two with positive feelings. Not surprisingly, the commonest concerns were those of loneliness, fears of suffering, pain and death. These were often accompanied by anger, loss of control and lack of being loved. Also noted was a recurring theme of "not being remembered". Balanced against these are more positive feelings of faith in God, forgiveness, repentance and reconciliation.

**Discussion:** Although appropriate counselling interventions can certainly help reduce distress, for many patients, there were residual, ongoing psycho-spiritual issues. While some of these were predictable, the significance or impact of others had not been anticipated. A detailed analysis of these will be presented. Careful evaluation of the patients' concerns has helped to shape our own approach in responding to these needs and will form the basis for ongoing and future detailed studies.

**Key words:** Cancer patients, Hospice, Psycho-spiritual concerns

## OD-32

**THE SCOPE OF COUNSELLING AND SOCIAL WORK IN AN IN-PATIENT HOSPICE SETTING**

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**Background:** Good palliative care relies on an integrated multi-disciplinary approach. However, certain aspects naturally fall within the remit of the counselling team. Psycho-social support and spiritual support are deemed to be as important as physical care, particularly towards the end of life.

**Objective:** This study was initiated to explore the scope of such work as a prelude to establishing the range of activities to be addressed in future, determine the areas where support is most needed and form the basis for future studies.

**Methods:** Notes of 25 patients with cancer were selected randomly and retrospectively from the past two years. Using structured pro-forma already in use, common themes of concern were documented and analysed.

**Results:** Social aspects that dominated included advocacy, legal issues, housing, tracing family members and reconciliation, financial issues, and fostering and placement of children.

Using four case studies as examples, this paper demonstrates the wide social work component of the counsellor's role and enumerates the varied tasks involved. It also highlights some of the challenges of the job, the barriers encountered and the numerous connections that need to be made outside of the hospice. In part these reflect the changing attitudes of society, availability of support and structure within families.

**Discussion:** Although many issues could be resolved with appropriate counselling, we also identified several residual concerns which persisted despite intervention. Evidence obtained strongly indicates that the need to engage, educate and empower the family members is crucial in ensuring a good outcome.

**Key words:** Counsellors, Hospice, Social work

## OD-33

**THE INFLUENCE OF DEMOGRAPHIC AND THE PSYCHO-SOCIAL FACTORS ON THE INTENSITY OF PAIN MANIFESTATION AMONG CHRONIC PATIENTS UNDER HOME-BASED NURSING CARE**

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**Background:** Psycho-social support influences disease manifestations and helps in coping with illness in chronic patients. The socio-economic status also plays a role in maintaining interpersonal relationships. Good social support

helps chronic patients to adapt and achieve a reasonable level quality in life, in spite of the disease. In this context, this study aimed to determine the influence of demographic and psycho-social factors on the intensity of pain manifestation among chronic patients.

**Methodology:** A questionnaire survey was conducted using MOS SF Health Survey among patients who registered with home care service, Ernakulam GH, Kerala, India, during the months of July to August 2015, after obtaining IEC permission, St. Gregorious Dental College & Research Centre, under KUHAS. The obtained data was analysed using Statistical Package for Social Sciences (SPSS) v.20.

**Results:** 64 out of 328 patients (19.51%), shows pain as a primary symptom of their disease. The analysis shows a significant relation of pain incidence with demographic factors as well as the level of social interaction. The incidence of pain increases with the level of education 8% in illiterates, 19% in middle level education and 46% in graduates ( $P = 0.002$ ). Pain sensation also increases with the monthly income 12%, 23%, and 28% in poor, middle and high income groups respectively ( $P = 0.019$ ). A higher degree of social interaction is associated with lower pain intensity ( $P = 0.019$ ).

**Conclusion:** Demographic factors have a significant effect on the social and emotional support to chronic patients under home-based health care and a strong social interaction reduces the pain intensity in them. The study concluded with a suggestion that a societal improvement in education and economic status will increase the level of social support and thereby the quality of life of chronic patients.

**Key words:** Chronic patients, Demographic factors, Pain incidence, Pain intensity, Social factors

## OD-34

**EMOTIONS IN HEALTH ASSISTANTS FOLLOWING THE DEATH OF A PATIENT IN THE HOSPICE**

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**Background:** Most of our Health Assistants (HA) come from rural, low socio-economic backgrounds and leave school at the 10th standard. Following a residential, six-month, hands-on training programme, they continue working as part of the team in the in-patient wards. Informal discussions with a few revealed several strong emotions following the death of a patient, especially as none had any experience of death previously.

**Objective:** To explore these feelings further by including views from the whole group to determine significant issues.

**Method:** Through informal discussions either in small groups or individually, HAs were encouraged to talk about

their concerns following the death of patients in their care. Two counsellors noted issues raised and collated the findings. Sixteen HAs contributed to the discussions and all were happy to partake. Six had less than 12 months of experience and four had been on staff for more than five years.

**Results:** Several common fears emerged: fear of touching a dead body, performing post-mortem procedures/“last offices”, worrying about catching a disease (cancer/HIV/ infection), sorrow, anger towards the family (abandoned patients), anger towards God (for allowing suffering), superstitions, fear of their own families’ reaction on returning to their village/ community, damage to their own marriage prospects.

Positive feelings included: respect for the dead, relief that suffering was over, good memories of dealing with the patient, carrying out their wishes.

**Discussion:** Some concerns changed with time and experience and these will be discussed further. These findings have highlighted the need for ongoing support for HAs beyond their induction period, on-going education and the provision of counselling when needed. A more structured, detailed study is planned.

**Key words:** Health assistants, Hospice, Post-death experiences

#### OD-35

### NAUSEA AND VOMITING IN ADVANCED CANCER PATIENTS: A RETROSPECTIVE ASSESSMENT OF THE USE OF OLANZAPINE AS AN ANTI-EMETIC

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**Background:** Nausea, vomiting and related symptoms can occur as a direct result of malignancy or as a result of its treatment. These symptoms can be very distressing to the patient and may also have significant physiological consequences. In addition, cancer patients may frequently also develop marked anorexia and become extremely cachectic. With this background this study was designed to perform a retrospective analysis of the use of olanzapine in controlling nausea and vomiting in patients with advanced cancer.

**Methods:** In this retrospective study, 50 patients who presented to OPD with chief complaints of nausea and vomiting and who were prescribed olanzapine were identified via the hospital database. They were stratified into type of cancer, age group, sex distribution and duration since last chemotherapy received.

The primary end-point was taken as the overall rate of patients achieving a complete response (defined as no episode of emesis and no use of any other rescue anti-emetic medications) and the secondary end-point was safety and tolerability with respect to any adverse drug reaction with a causal relationship to olanzapine.

**Results:** Of the 50 patients who were prescribed olanzapine, 76.5% were female while 23.5% were male. Majority of the patients were in the age group of more than 60 years. Majority of the patients had primarily GI malignancies. 61.7% of patients achieved the primary end-point of achieving a complete response (CR) with an average time to CR ranging between two and ten days. There were no major safety concerns with respect to use of olanzapine.

**Conclusion:** Use of olanzapine proved to be a beneficial intervention in controlling nausea and vomiting in advanced cancer patients. This pilot retrospective study provides a futuristic pathway for conducting a prospective study on the usage of olanzapine in the treatment of nausea and vomiting in cancer patients.

**Key words:** Cancer, Nausea, Retrospective, Vomiting

#### OD-36

### IMPACT OF CHILDREN’S PALLIATIVE CARE PROJECT ON THE QUALITY OF LIFE OF CHILDREN FROM TERTIARY CENTRES IN MAHARASHTRA

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**Background:** Life-limiting conditions like congenital disorders, cancer, HIV and thalassemia prevent children from enjoying the quality of life that would normally be enjoyed by children. Quality of life of these children can improve to a certain extent when holistic care is provided by a multidisciplinary team.

**Methods:** Children enrolled under CPC project from two sites were provided holistic care by multidisciplinary team. Peds QOL questionnaire was administered at every visit of the child to the centre. The data was collected with SPSS software. It was analysed by paired T test for 577 samples.

**Results:** Quality of life with respect to physical functioning improved to a certain extent but with respect to emotional functioning, it improved from 28% to 60% and with social functioning it improved from 43% to 70%.



**Conclusion:** Holistic care by a multidisciplinary team, with emphasis on adherence to symptomatic treatment, counselling, networking with schools and NGOs, and referrals to supportive and rehabilitation care, improves quality of life of children to a great extent.

**Key words:** Children, Physical, Psychosocial, Quality of life, Spiritual

#### OD-37

### PATIENT SATISFACTION OF HOMECARE SERVICE PROVIDED THROUGH E-PALLIATIVE HOMECARE SERVICE IN A TERTIARY CANCER CENTRE OF NORTHERN KERALA: A PILOT STUDY

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**Introduction:** Palliative care remains the most important and underutilized modality for cancer patients presenting in advance stage. Evidence is emerging that cost effective palliative care services can be provided by home based services. The homecare service provided by Malabar Cancer Centre is nurse-led and physician-assisted. In this study, we want to explore the concept of e-palliative medicine wherein the patients can be seen and communicated to by the palliative physician sitting in the hospital. We also want to assess the level of patient satisfaction of e-palliative home care services provided by Malabar Cancer Centre.

**Aim:** To find out the level of satisfaction of patients receiving e-palliative homecare service from Malabar Cancer Centre, using the validated E-Palliative Patient Satisfaction Questionnaire.

**Method:** A pilot study was done in 30 patients. After providing the information sheet and taking a written informed consent, each patient was given the validated E-Palliative Patient Satisfaction Questionnaire by the homecare nurse after the patient was consulted by the doctor through e-palliative care. The questionnaire consisted of 15 statements and there were five response options. If a patient could not read or was not in a state to comprehend the questionnaire, it was given to a close caretaker. Basic descriptive analysis was performed to compute the distribution of observed responses to obtain the level of satisfaction of patients receiving e-palliative homecare service.

**Results:** The median score of response for general satisfaction was observed as 4.00. The median score of response for technical quality, communication, financial aspect, time spent with doctor, and accessibility and convenience was observed as 4.00, 4.00, 5.00, 4.00, and 4.33, respectively.

**Conclusion:** The overall satisfaction of patients receiving e-palliative homecare service from Malabar Cancer Centre is high. E-palliative care is a feasible option for providing excellent palliative care in developing countries with limited resources and financial constraints.

#### OD-38

### BURNOUT IN PALLIATIVE CARE PROFESSIONALS IN MUMBAI: A CROSS SECTIONAL STUDY

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**Introduction:** Burnout has been reported in palliative care professionals. Indian studies have looked at this phenomenon in staff working with HIV-affected patients. The purpose of our study is to evaluate the presence and degree of burnout in palliative care professionals in Mumbai and to look at the factors associated with it.

**Methods:** A cross-sectional questionnaire survey was carried out among palliative care professionals using the Maslach Burnout Inventory (MBI), after ethical approval. Data was collected on participants' demography, palliative care profession, work setting, number of years in palliative care, perceived sense of alignment with organizational ethos and scores on MBI. Descriptive statistics were used for respondent characteristics and MBI scores on the three domains of Emotional Exhaustion (EE), Depersonalization (DP) and Personal Accomplishment (PA). Chi square tests were used to examine association between various factors and burnout score on MBI.

**Results:** Of the 32 study participants, 14 were doctors and 18 nurses. 24 were females. The mean age was 37.4 years (SD 9.9). 16 participants had 2-5 years of palliative care experience. 30 participants worked full time in specialist palliative and hospice care setting. The mean scores were 10.3, 8.2 and 32.9 in EE, DP and PA respectively. 53% participants had high levels of burnout in at least one domain. All participants perceived that their work ethos matched that of their organizations'. There was no significant association between burnout level and age, gender or number of years of experience in palliative care.

**Conclusion:** We noted a high level of burnout in at least one domain of EE, DP and PA in 53% of participants. All participants' perceived work ethos aligned with that of their organizations. Burnout in palliative care professionals needs to be identified, for instituting appropriate interventions to improve their health and work satisfaction.

**Key words:** Burnout, Palliative care professionals

**OD-39****ROLE OF STAFF NURSE IN LYMPHOEDEMA CARE IN POST-OP MASTECTOMY PATIENTS****Sis. Revathi, Sweta Ben, Priti Sanghavi, Geeta Joshi**Department of Palliative Medicine, Gujarat Cancer and Research Institute, Ahmedabad, Gujarat, India  
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**Introduction:** Lymphoedema is defined as “swelling due to the excess accumulation of fluid in the tissues caused by inadequate lymphatic drainage”. It is a chronic condition which causes physical and psychosocial problems to the patients. Its incidence varies from 8% to 56% at two years, post-surgery. Nurses play an important role in the management of lymphoedema.

**Objective:** To determine the role of trained nurses in the management and reduction of morbidity in patients with lymphoedema.

**Method:** The study was conducted at Gujarat Cancer and Research Institute, Ahmedabad. The patients who had undergone MRM during the period January to June 2015 were included. Out of the 179 patients who underwent MRM, 164 developed lymphoedema. The role of nursing in the management of lymphoedema in these 164 patients was assessed.

**Discussion and conclusion:** Nurses, being present in wards throughout the day, can create an excellent rapport with the patients. Thereby they can help patients cope well with their disturbed body image, and their fears and anxiety. Along with psychological support, nurses also help with physical issues like skin care, ambulation and positioning of the affected limb, and promote comfort measures for the patients. They can also help with pneumatic compression, compression sleeves and physiotherapy. They can monitor the patients daily for pain, injury, signs of pulmonary emboli and signs of infection and then can refer to the concerned specialist, if necessary. Thus, specially trained nursing staff can play a pivotal role in the management of lymphoedema and help in reducing the morbidity of the patients.

**Key words:** Lymphoedema, Morbidity, Nursing, Trained nurses

**OD-40****AN EXPERIENTIAL ACCOUNT ON GERIATRIC ASSISTED LIVING AND DEMENTIA CARE****Muralidhara CP**

With a population of about 90 million elderly in India which is expected to grow to 173 million by 2026, the need for a geriatric care system is growing. People affected with physical

disabilities due to geriatric illnesses generally need care either at home or at professional centres. Awareness about assisted living is very poor and there are only a few facilities available in India. Stigma attached to traditional old age homes is a hindrance for people in taking decisions to shift to Care Homes. There is no formal structure available to run assisted living centres and dementia care centres, neither is there any organized training available for geriatric care givers. Operationally, we experienced various challenges like financial viability, acceptance of the concept among public, sales and marketing, awareness building, staff sourcing, training and retention and so on. With no Indian model to follow, we had to build the centre based on “learn from experience” method. Managing challenging behaviour of seniors, and the irrational expectations of family members were ladders for our learning. Assisted living is different from living in a hotel and it is not a hospital as well. Our efforts are to make it very much like home while maintaining it professionally. Setting a meaningful calendar of activities for physical and mental health and following it to the best possible extent is a must in an assisted living facility. There is a whole world of learning and opportunities available to welcome people who are interested in this field.

**OD-41****PROCEDURAL PAIN MANAGEMENT: A MUTUAL PARTICIPATION MODEL IN A FAMILY-CENTRED CARE APPROACH****Huma Anis<sup>1,2</sup>**<sup>1</sup>Senior Psychologist, <sup>2</sup>General Manager, Paediatric Psycho-oncology Programme, Cankids...Kidscan, New Delhi, India  
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**Background:** Children with cancer face pain, not only from their illness, but from the many procedures required to diagnose, monitor and treat their disease. Frequent venepuncture, cannulation, bone marrow aspiration, lumbar puncture and dressing changes causes both physical pain and psychological distress, which may lead to behavioural changes and aversion to hospital, making cancer care more stressful and difficult. Our purpose is to present a non-pharmacological approach, for the management of procedural pain in children.

**Methods:** A previous needs assessment and a cancer centre pilot project plus a recent literature review, led Cankids Psycho-oncology Department to develop a Non-Pharmacological Participation Model, to manage procedural pain in children. The model incorporates a variety of environmental, positional, behavioural, psychological, and educational approaches, to reduce children's procedural pain and promote

coping. Therapeutic use of play, storytelling, distraction, clown therapy and “handy candy” are employed within the model, together with more formal psychotherapeutic approaches such as counselling and hypnosis. This model empowers parents and professional carers, through close collaboration, active participation and shared understanding, to reduce procedural pain. The model can be used alone or as an adjunct to pharmacological management.

**Results:** The interventions described within this “mutual collaboration model” have been shown to reduce procedural pain in children and empower parents to take an active role in their child’s management, to help them cope and hopefully improve their experience of cancer care. Training hospital staff to use the model, will provide an early contact with Cankids palliative and supportive care services, strengthening working partnerships.

**Conclusion:** Our “Mutual Participation Model” will lessen procedural pain for children with cancer and will help build strong relationships with partnering doctors. This model will facilitate non-pharmacological approaches in local cancer centres, providing informational and educational tools and training to the parents and staff members. We will be able to educate and empower families, staff and paediatric palliative care teams in medical support, patient navigation, emotional support and counselling.

**Key words:** Child life, Non-pharmacological interventions, Paediatric psycho-oncology, Pain management, Procedural pain

#### OD-42

### NURSING INTERVENTION IN SYMPTOM MANAGEMENT AT DEPARTMENT OF PALLIATIVE MEDICINE AT TATA MEMORIAL CENTRE, MUMBAI

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**Background:** Life-limiting conditions bring pain and other unpleasant symptoms for the patients which affect the quality of life of patients and their family members. It is important to understand the difficulties faced by patients when referred for palliative care. The role of nurses is very important in symptom assessment, management and counselling patients and their family members, including at end of life.

**Methods:** In the Department of Palliative Medicine, Tata Memorial Centre, the following practices are used to provide quality care to patients:

1. Assessment of patients with a holistic approach.
2. Management of pain and distressing symptoms, e.g. fungating wound care, stoma care, excessive bleeding, etc.

3. Counselling patients and family members about positive thinking towards death.
4. Empowering family members to take good care of patients by educating them about RT feeding, oral care, hygiene, prevention of bedsores, nutrition, etc.
5. Guidance to patients about various supportive care, e.g. help from various NGOs, rehabilitation, occupational therapy, etc.
6. Ensuring drug adherence.
7. Follow up with patients through phone calls.
8. Home care services with multidisciplinary team.
9. End-of-life care.
10. Bereavement support to the family members.

**Result:** Pain and symptom relief helps patients and their families in coping with the disease process. Counselling and empowerment of patients and family members helps them to cope with psychological distress. Financial aid and other supportive measures are an essential part for those families who face difficulties in adjusting to the reality of advancing disease. At end of life, a peaceful and natural death is made possible for majority of patients.

**Conclusion:** The nurse is the pivot around which care for patients and their families with advanced disease revolves. Their active intervention helps in symptom assessment and management, along with counselling. This is an example of comprehensive nursing care.

**Key words:** Counseling, Nursing care, Symptom management

#### OD-43

### PREVALENCE AND INTENSITY OF DYSPNOEA IN ADVANCED CANCER AND ITS IMPACT ON QUALITY OF LIFE

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**Background:** Dyspnoea is a subjective, multidimensional experience of breathing discomfort, commonly seen in patients with advanced cancer that influences all aspects of patient’s life. To find the impact of dyspnoea on the quality of life in this population, it is important to understand the prevalence and factors influencing dyspnoea.

**Aim:** The aim of this study was to determine the prevalence, intensity and factors influencing dyspnoea in advanced cancer and determine its impact on overall quality of life.

**Methods:** The study was a prospective cross-sectional study. Prevalence of dyspnoea and its impact on quality of life was determined on 500 patients registered with Palliative Medicine

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OPD. The patients were asked to fill a set of questionnaires, which included the Cancer Dyspnoea Scale (translated and validated Hindi and Marathi versions), Visual Analogue Scale for dyspnoea and EORTC QLQ C 15 PAL. Other details of symptoms, disease, treatment and the demographics were collected from the case record form of the patient. Descriptive statistics, univariate and multiple regression analysis were used to calculate results.

**Results:** 44.37% of the patients experienced dyspnoea. The factors of dyspnoea increased with increase in anxiety, depression, fatigue, loss of appetite, loss of wellbeing, pain, lung involvement by primary or metastatic disease, performance status and deteriorating overall quality of life and emotional wellbeing on EORTC QLQ C15 PAL.

**Conclusions:** Prevalence of dyspnoea in advanced cancer population is as high as 44.37% and it causes a negative impact on overall quality of life of patients.

#### OD-44

### INDIAN PERSPECTIVE ON ADVANCED DIRECTIVES IN A HOSPICE

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**Background:** From the Indian perspective, patients are not comfortable talking about death, let alone planning and giving advanced directives. In our hospice, where 3 to 4 deaths occur every week on an average, we have tried to incorporate planning for death and afterwards, especially in some cases where there are no kith or kin to take care of these things. In most of the patients, the care givers take many decisions of end of life and also afterwards.

**Methods:** We have done a retrospective study of the patients in our centre where death-related decisions were made by the patients themselves. We examined 50 deaths in our centre. We examined the before-death conversations which were recorded in the case file to look for advanced planning or directives.

**Results:** In 90% of the cases, there was no talk about end-of-life planning even when the patient was aware of impending death. Such conversation was available only in 10% of patients and planning for the last rites of the patient or the care for the orphaned children was done only in a few instances.

**Conclusions:** We tried to explore the reasons for these results and realized that it was not just the attitude of the patients or the caregivers. Even the staff at the hospice was uncomfortable talking about the death plans and post-death instructions or directives. In the few cases we were required to plan these for the patients, we were unsure of the legal and other implications.

**Key words:** Advanced directives, End of life, Hospice

#### OD-45

### SPIRITUALITY IN PALLIATIVE CARE

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Spiritual care is to be fully utilized as a resource in provision of clinical care, education of future healthcare leaders and advancement of the science and practice of medicine. It's about integrating patient's spiritual beliefs into their care, addressing sensitive medical issues facing seriously ill patients and supporting health care professionals in their provision of compassionate care. It also includes various dimensions of palliative medicine such as depression, desire for death, will to live and dignity at the end of life. Spiritual care gives motivation to provide compassionate care that is sensitive to the types of emotional and mental distress that accompany mental illness. During illness it becomes important to understand how the relationship works. I recollect an incident when I met Madam Julie Adams, a cancer patient in advanced stage, with few weeks of life left, at Washington DC. She was in the stage of denial for the treatment but wanted to live without bothering her family. It was difficult to read her mind. However, I initiated the conversation as the leader of the group involving physicians, the chaplain, palliative care giver and social worker. While others found it difficult to break the ice, I left my place, went to hold her cold hand after which she felt a bit relaxed and shared concerns. She was depressed due to his son's sudden death and worried about her family. She was not sure that after treatment she would be fine or her life would get shorter, starving the family. I could get her to relax finally. In the feedback session, she specially appreciated my touch therapy and happily posed for a photograph, on my request. Patients want their caregivers to talk with them on spiritual needs to address their spiritual issues but only very few actually having these conversations with their physicians.

#### OD-46

### FOOD INTAKE UNDER PALLIATIVE CARE: PERCEPTIONS AND EXPECTATIONS OF PATIENTS SUFFERING FROM ORAL CANCER AND THEIR CAREGIVERS

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Loss of appetite is one of the first and most common symptoms in cancer. As the disease progresses, the patient's food intake is affected drastically. Our society emphasizes the correlation between high food intake and good health. This study captured the perceptions and expectations about patient

intake through a survey of 30 primary caregivers as well as their patients suffering from oral cancer and undergoing palliative care. The results indicated that the caregiver emphasized more on improvement in intake, believing that it would improve the patient's immunity and give him the strength to overcome his cancer. This also led to higher frustration levels in both groups. This highlighted the need for regulating expectations through nutritional counselling.

**Key words:** Expectation caregivers, Nutrition, Palliative care, Perception

#### OD-47

#### WHAT MOTIVATES AND ENGAGES THE VOLUNTEER: AN IN-DEPTH INTERVIEW

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Medical milestones are memorable, but the quality of life rests on every day events. With all the efforts from varying specialists, something more can always be done for the patients. With a large number of patients needing medical attention and professional intervention, the palliative care staff struggles to meet their needs. They run short of the energy to support the patients and their families. Here, volunteers play an important role in furthering the Centre's objectives and services. The unfailing support of the volunteers has helped to fill the gaps in the Centre's palliative care delivery. The study explored the motivating factors, which draw the volunteers towards the organisation. Ten volunteers, who have been associated with the Centre for at least 10 years, were interviewed in depth. Their responses were analysed qualitatively for common themes. The results showed that the feeling of contribution to a cause has a great influence on the volunteers. An altruistic bent of mind and having one's life touched by tragedy are major motivating factors.

**Key words:** Palliative care, Organisational engagement, Volunteers

#### OD-48

#### GLOSSOPHARYNGEAL NERVE RADIOFREQUENCY ABLATION: ROLE IN PAIN RELIEF AND MAINTAINING GOOD QUALITY OF LIFE IN CANCER TONGUE PATIENTS, A RETROSPECTIVE ANALYSIS

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**Background:** Patients with Ca tongue can present with repeated episodes of intractable pain in the tongue, throat, tonsils and ears. The treatment of these patients with persistent severe pain often requires a multidisciplinary approach. Use of the glossopharyngeal nerve RFA technique is a useful alternative for treatment of cancer of tongue.

**Methods:** A retrospective study was designed to observe the effectiveness of glossopharyngeal RFA in relieving pain in patients with carcinoma base of tongue. The study was done in 70 patients who were admitted from January 2014 to December 2015 with Ca tongue for glossopharyngeal nerve RFA. NRS score was used to assess pain score.

**Results:** Improvement of quality of life, significant decrease of requirements of opioid and non-opioid analgesic doses. Long term effect: Two complications appeared with temporary swallowing problem and hoarseness of voice (six hours).

**Conclusion:** Glossopharyngeal nerve block is effective in patients with Ca tongue in relieving baseline pain as well as pain during coughing, swallowing, chewing, speaking and laughing. Intervention during the early stages of pain treatment can therefore bypass these problems, decrease the analgesic requirements and increase the faith of the patient in the pain physician.

**Key words:** Carcinoma tongue, Glossopharyngeal nerve radiofrequency ablation

#### OD-49

#### A REVIEW TO IDENTIFY THE EXTENT OF GENDER MAINSTREAMING IN PALLIATIVE CARE RESEARCH

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**Background:** Palliative care aims to improve the quality of life of patients and families facing life-limiting illnesses by impeccable assessment and management of problems across multiple domains physical, psychosocial and spiritual. Gender considerations are therefore inbuilt into this description but the extent to which these are realized is not clear.

**Objective:** To understand the role of gender in various aspects of palliative care.

**Methods:** A PubMed search with the terms "palliative care", "sex" and "gender" was done, with limits set at full paper available online. Papers were screened for extent of inclusion of gender considerations and the WHO gender analysis framework was used to categorize papers based on coverage of gender issues.

**Results:** A total of 102 papers were listed as part of the search strategy of which 22 were excluded. Most of the papers were from Europe including the UK (41) and none was from India. Gender was mentioned in the objective of 26 papers (32.5%) but 5 of these did not address gender in any way. Only 12 (15.0%) papers had substantial gender considerations on parental roles and circumstances associated with in bereavement or life-limiting illness in children, three on gendered aspects of care giving, one each on precarious masculinity in testicular cancer survivors, gender issues in organizational structure, palliative care nurses, patient referral pattern to palliative care and expectations from volunteers. Biological differences were the predominant characteristic listed in many of the other papers. One paper had mentioned the gender transformative role of palliative care.

**Conclusions:** Gender considerations do figure in research discourse in palliative care but mostly in developed countries and is often limited to sex differential analyses. A lot of the discourse use sex and gender interchangeably suggesting the need for gender mainstreaming in palliative care research.

**Key words:** Gender role analysis, Palliative care research, Sex differences

#### OD-50

### AMBULATORY SUPPORT FOR CHILDREN UNDERGOING TREATMENT FOR CANCER PROVIDES AN OPPORTUNITY FOR EARLY ACCESS TO PALLIATIVE CARE AS AN INTEGRAL COMPONENT OF PAEDIATRIC CANCER CARE IN INDIA

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**Background:** Only 20-30 percent of children diagnosed with cancer in India survive and yet palliative care, often perceived as synonymous with death and dying, is seen as a last resort, rather than an integral component of holistic cancer care. Palliative care provision for children, developed as an extension of existing adult services with dedicated paediatric support, is now emerging. Integration with mainstream cancer services is lacking and remains a problem. Cankids opened a palliative care unit, (Day Care Transition Home, DCTH) in Delhi to provide 24 hr multi-disciplinary support for children with cancer, and their families. An ambulatory clinic was set up at DCTH to administer IV antibiotics and GCSF injections at weekends and statutory holidays following a request from the Paediatric Oncology Department at AIIMS.

**Method:** Policies and procedures for administration were jointly agreed, key workers identified and training provided

for nursing staff. A Letter of Understanding was drawn up and signed by senior staff from both organisations.

**Results:** Ambulatory clinic attendance increased steadily within safe limits. It offers brief respite in a child-friendly, relaxed environment where play is encouraged and nutritious food is provided. Holistic nursing assessment identifies symptoms requiring palliation, wounds are dressed and parents advised on health, hygiene and comfort measures. Parents and children meet with an experienced volunteer, trained to navigate and support families through their cancer journey. The ambulatory clinic provides an early introduction to palliative care for children with cancer, strengthens working relations between teams and empowers nurses to support children and families and maintain practical skills.

**Key words:** Ambulatory, Collaboration, Holistic, Integration, Intravenous treatment

#### OD-51

### EARLY INVOLVEMENT WITH PAEDIATRIC PALLIATIVE CARE TO IMPROVE THE QUALITY OF LIVING WITH, AND DYING FROM PRIMARY BONE TUMOURS: A REVIEW OF RECENT CASES AT CANKIDS, DELHI

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**Background:** Primary bone cancers account for around 5% of childhood cancer in India. Children often present late, with pain and reduced function to face complex investigations and costly, disfiguring treatment. The outcome for these children remains poor, but may be improved through early access to palliative care and support. A project to navigate and support children through the diagnosis and treatment of primary bone cancers was set up by Cankids in Delhi, to prevent delay, facilitate timely treatment and, hopefully, improve outcomes. Palliative care support is provided by the multidisciplinary team based at Cankids in-patient unit.

**Methods:** Case review of four children, recruited into the Bone Tumour Project at diagnosis and admitted to Cankids inpatient unit in September 2015, was undertaken by the author using information gathered from case notes, out patient records, ward rounds, MDT meetings, clinics, visits and conversations with the children and their families.

**Results:** There is clear evidence, from the cases reviewed, of the benefits gained by children with primary bone cancers and their parents from early palliative care support particularly with regards to pain and symptom control, help in understanding information and making difficult decisions,

as well as financial support for treatment. Encouragement to continue with studies, set realistic goals and “make a wish” helped maintain hope in the face of progressive disease, whilst holistic nursing care, sensitive communication, symptom management and planning at the end of life, helped achieve a good death.

**Key words:** Communication, Holistic, Symptoms, Timely decisions

#### OD-52

### VALIDATION OF THE MALAYALAM VERSION OF DISTRESS THERMOMETER

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**Introduction:** Distress is a common concern in cancer patients, beginning at diagnosis and extending to post-treatment phase. Heightened distress is associated with worse health-related quality of life, lesser treatment adherence, lower satisfaction with care, and possibly lower survival. However, distress evaluation and treatment is neglected care in India. NCCN distress thermometer is a quick-screening tool to identify actionable distress. But it is in English language and there is no Malayalam version. Hence, this study was planned to develop the Malayalam version of distress thermometer and test its feasibility on our patients.

**Aim:** To translate and validate NCCN distress thermometer into Malayalam language. To study the feasibility of using this validated Malayalam translated distress thermometer.

**Methods:** This is a single-arm prospective study. Cancer patients with ECOG PS 0-2, having knowledge of English and Malayalam and willing to complete the study questionnaire were included after written informed consent. It was done in 2 phases. Phase 1 included a translation of the NCCN distress thermometer into Malayalam language with a forward-backward translation procedure. In phase 2A the post validation of the proformas was conducted on a total of 10 patients. A proforma was considered to be complete, if it was more than 80% filled. The descriptive statistics of response to QQ10 tool was used for consideration of feasibility, face validity and utility. A total of 10 patients were included as it was a pilot study.

**Results:** The proformas were completed by all patients (100%). The responses confirming the utility and face validity of the proforma were 100%. For feasibility, 80% and above patients responded positively to all questions.

**Conclusion:** It can be concluded that the Malayalam Distress

Thermometer has high face validity, utility and its feasible for use.

**Key words:** Distress, Feasibility, Validation, Utility

#### OD-53

### DELAYED PRESENTATION AND POOR PROGNOSIS OF METASTATIC SPINAL CORD COMPRESSION: AWARENESS IS THE NEED OF THE HOUR

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**Background:** Metastatic Spinal Cord Compression (MSCC) is a major cause of morbidity in cancer patients. Incidence of MSCC is unknown. Since, better survival outcomes are observed with advancement in cancer treatment, incidence is likely to increase in the coming future. MSCC, if left obscured may lead to irreversible neurological damage that may ensue paraplegia. Hence, early diagnosis and treatment is essential.

**Objective:** To increase awareness among health care professionals and patients for early recognition of symptoms and prompt treatment.

**Method:** A retrospective study was designed to observe the varied presentations of patients with impending or established MSCC.

**Results:** 10 patients were identified as having MSCC over a period of 6 months (July-December 2015). Most common presentation was pain in back. Site varied from low back to whole spine depending on extent of metastasis. Average NRS on admission was 8/10. In nature, radiating pain was observed in 5 patients. Out of these 5 patients, 3 had associated motor weakness. Time between symptom onset and presentation ranged between 3 days to 2½ months. Although there was no delay in admission and start of the treatment that comprised steroid cover with dexamethasone, radiation therapy, surgical intervention, those patients who presented with motor weakness had poor prognosis. Only 1 patient who presented within 3 days of onset of symptoms had better neurological outcome as early surgical intervention was possible and planned.

**Conclusion:** MSCC remains a dreaded complication of cancer encountered in clinical practice. This study provides insight to increase awareness about early recognition of symptoms among patients who are at risk of MSCC during hospital visits that may help the patient escape the physical and emotional trauma of paraplegia.

**Key words:** Awareness, Metastatic spinal cord compression, Prognosis

**OD-54**

**HOMEOPATHIC INTERVENTION IN PAIN MANAGEMENT**

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NTPC Northern Regional Headquarters took the lead in funding Cancer Aid Society for establishment of a free dispensary aiming to provide cost-effective treatment in palliative care using homeopathic remedy for pain relief, which are free from side effects and have demonstrated good results in the patients treated by me involving free consultation along with distribution of free medicine for acute and chronic ill patients. The homeopathic approach towards symptomatic treatment for the pain management of the patients and its impact on their quality of life has been documented for hundred patients attending the homeopathic

clinic. Homeopathic Treatment is based on analysing physical ailments, mental symptoms along with peculiar symptoms if any, and based on the same, which involved consultation up to 60 minutes each, prescription was prepared and homeopathic remedy given. The effect these symptoms have on the daily life and overall sense of wellbeing were recorded prior to medication. The patients completed a final assessment about the efficacy of the treatment through questionnaire and feedback about satisfaction with the homeopathic treatment, how helpful they had found the approach for the targeted symptoms and what factors they felt may have contributed to the perceived changes. This study was focused on the pain management. However, treatment covered a variety of other symptoms effectively. Majority of the patients were satisfied and rated the approach as helpful or very helpful for their symptoms. In fact, homeopathic medicines are cost effective, to the extent of Rs. 2 per day, which is cheaper as compared to other medicines used in pain management in palliative care and they also have no side effects, even on long term use.