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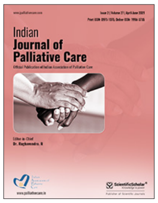

Oral Presentation

OP-05_1

Healing the mind, body and spirit: Spiritual exploration in Indian Palliative Cancer Care

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Palliative care encompasses a patient-centred, organismic, transcultural and holistic approach to address the varied needs of a patient, to include, physical, psychological, social, emotional and spiritual. The study aimed to explore the role and implications of the spiritual component of palliative cancer care in Indian Context. It explored the spectrum of spiritual well-being, factors that affect provision of spiritual care and probable spiritual intervention to facilitate the patient's journey towards spiritual wholeness and holistic healing.

The study adopted a pragmatic exploratory approach. Interviews with interventionists (n= 11), patients (n= 4), and caregivers (n= 5) were conducted to elicit information with respect to the practical aspects, implications and challenges to providing spiritual care as part of palliative care. Contextualist thematic analysis was used in an attempt to reflect reality of experiences, meanings of participants while also identifying the larger context and discourses operating within the society. Findings revealed locus of control, community strength, acceptance, forgiveness, coping mechanisms and existential coherence as mediating variables on the spectrum of spiritual well-being. Extraneous variables and protective factors apropos to spiritual well-being were highlighted. Additionally, potential spiritual interventions to facilitate communion with self, others, nature and the higher power, and barriers associated with providing spiritual care in Indian palliative cancer care were identified.

Results indicated that spirituality may have analgesic properties, facilitate building psychosocial support and community integration, act as an inoculant against anxiety, rumination and depression; foster positive coping strategies and decrease risky behavior; and help find a sense of meaning, or "existential coherence."

Key words: *Indian Palliative Cancer Care, spirituality, healing, spectrum of spiritual well-being, healing, pragmatic exploratory design, interventionists, caregivers, patients, mediating, extraneous variables, spiritual interventions.*

OP-06_2

Integrating Emotional Distress Treatment With Medical Management of the Palliative Patient: Missing links in the Delivery of Care

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Introduction: Integrating psychological treatment with medical management benefits the palliative care (PC) patient. **Aim:** To identify gaps in the assessment of Emotional Distress (ED) by the palliative care team (PCT) and to suggest a delivery care system which integrates mental health care with the PCT.

Method: During morning rounds over a six month period, 33 English speaking patients were asked by the PCT Psychologist about their ED using the NCI Distress Thermometer (NCIDT). PCT assessment of patient ED was also recorded.

Results: The PCT only asked about ED 20% of the time and tended to underestimate patient ED (mean estimated ED = 5 + 3). Patients reported moderate to high ED on a scale of 0-10 (mean ED = 8+2) on the NCIDT with anger, hopelessness, depression and anxiety as major symptoms. Patient's ED scores were frequently higher than their reported pain scores (mean pain score = 5 + 5) . Patients were 85% less likely to speak with the PCT regarding their emotional distress than to the psychologist. Patients reported less anxiety and pain when they received treatment of their ED symptoms by the psychologist using Cognitive Behavioral Therapy (CBT) and mindfulness techniques.

Conclusions: Gaps include lack of routine standardized assessment of ED by the PCT ; absence of a referral system to the psychologist; and a means to circle back to the PCT to report on patient ED in psychological treatment. A care delivery system which integrates treatment by the PCT and the PC Psychologist is discussed.

OP-12_5

Palliative Care Nursing Theory for Advanced Cancer Patients

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Introduction: There are a large number of patients with advanced cancers worldwide. There isn't much in the way of a defined theoretical framework for giving these individuals palliative care.

Aim: We aimed to construct and validate palliative care nursing theory for patients with advanced cancer.

Methods: All India Institute of Medical Sciences, Rishikesh, two department i.e., Radiation oncology and Surgery where this study was carried out. We used a mixed-methods approach in the current study, including both qualitative and quantitative techniques. In the qualitative study, guided content analysis was employed to sub-themes from exploratory surveys. In the quantitative study, prospective cohort methods were employed. The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life (QOL) scale was used to test the palliative care nursing theory on 80 patients with advanced gallbladder cancer and their caregivers over the course of six months. Survival rates were also evaluated.

Results: In the qualitative study, 25 patients were enrolled between July 2019 and December 2019. These four ideas i.e., symptomatic management, problem-solving counselling, yoga and meditation, and family or caregiver involvement are the foundation of the palliative care nursing theory. (Figure 1) We created a conceptual framework and a palliative care nursing theory from them. (Figure 2) Then, in the subsequent quantitative investigation, we examined this palliative care nursing theory in 80 patients with advanced cancer who were getting palliative care (40 in the interventional group and 40 in the control group). (Figure 3) We treated the patients in the interventional group in accordance with the recommendations of the palliative care nursing theory and discovered that this had a substantial positive impact on both overall survival and quality of life (P = 0.0001; 95% CI= 5.97–87.82).

Conclusions: A systematic and well-designed tool, validated palliative care nursing theory can be used to offer complete palliative care to advanced cancer patients. This can help palliative care teams give patients and their families with better palliative care.

Keywords: Palliative care nursing theory, advanced cancer patients, quality of life

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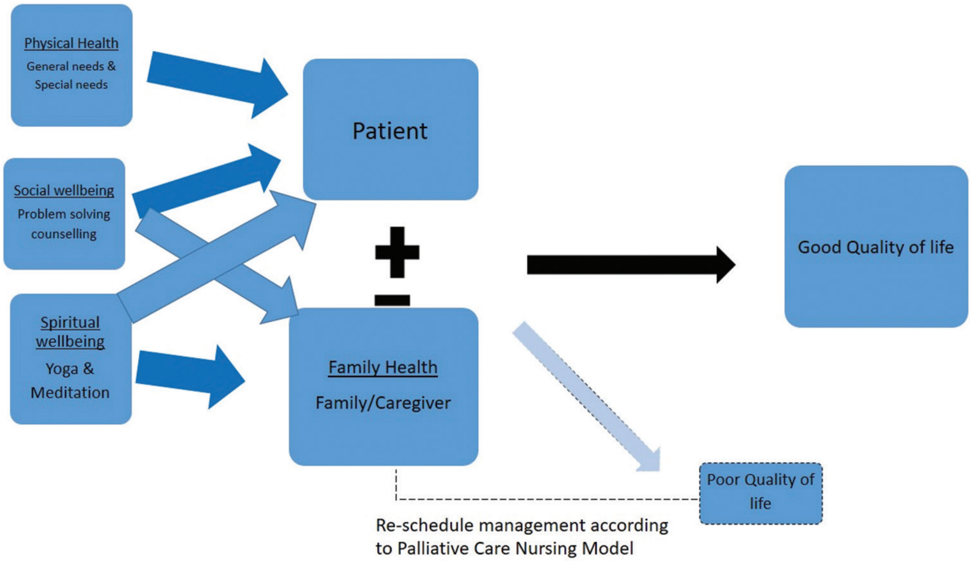

Figure 1: Framework for palliative care nursing theory.

OP-20_9

A Study of Burnout Among Palliative Care Professionals

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Introduction: Palliative care is a growing field all over the world, and with that comes demanding and stressful environments for its workers. Global meta-analyses have found that the prevalence of emotional exhaustion was 24%, the prevalence of depersonalization was 30%, and the prevalence of low personal accomplishment was 28%. These new studies have found high levels of these characteristics of burnout, but there seems to be a lack of data on the effects in India, specifically the state of Karnataka.

Aim: To analyze the prevalence of burnout among palliative care professionals across SVYM in Karnataka, India.

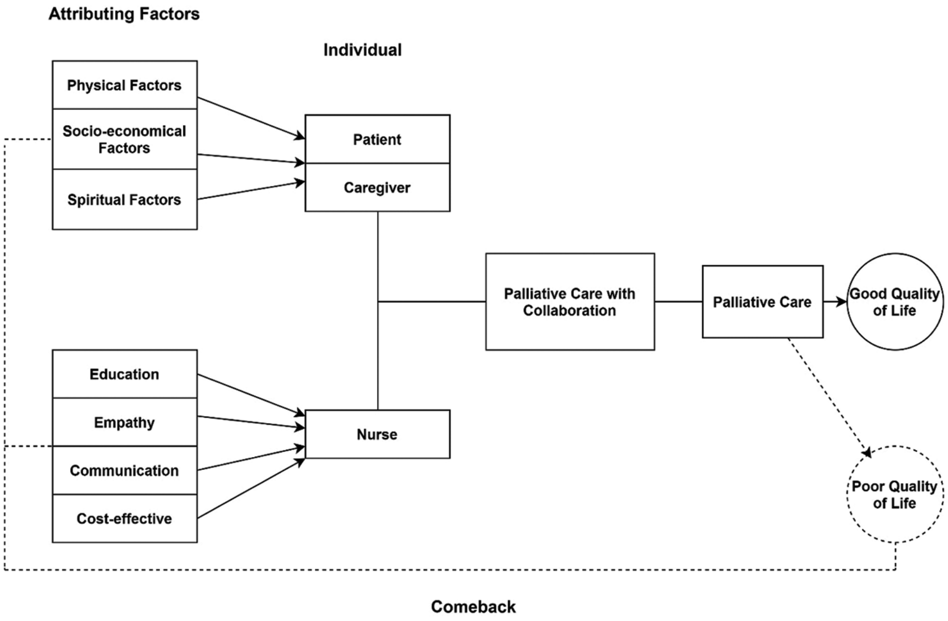

Figure 2: Palliative care nursing theory.

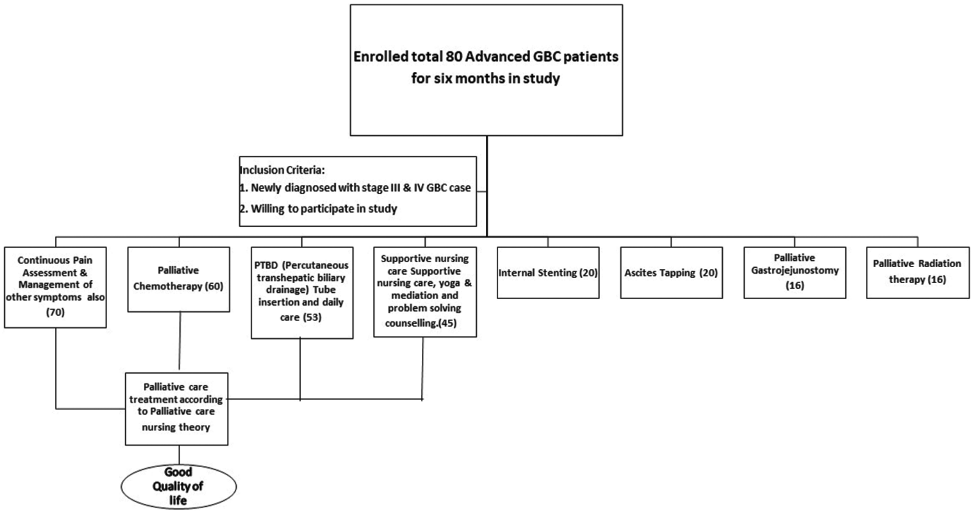

Figure 3: Palliative care nursing theory testing.

Materials and Methods: A cross sectional survey conducted using A pre-structured questionnaire containing socio-demographic details & Maslach Burnout Inventory (MBI). Participants were recruited through an email list of all employees at the SVYM Palliative Care Program, and were sent an email including the online questionnaire.

Results: A total of 22 professionals participated in the study. Among them 54%, 32% &14% from Mysuru, Hassan & Dharwad respectively. 49% were males. 54% working in both home care and institutional care and 46% working only at home care settings. Prevalence of burnout was 27%. As per MBI grades, 18% of the study participants had high depersonalization & low personal accomplishments. Workplace has significant association with burnout symptoms

Conclusion: Prevalence of burnout was low in the study population compared to other places. Burnout is associated with poor quality of care and negative effects on individuals; hence, early identification helps in formulating appropriate interventions.

OP-29_35

Competencies required from a nurse in palliative care - the view of nurses

Petra Auramo

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Introduction / Aims: The need to ensure proper competence of palliative care to nurses in undergraduate and specialist education is recognized. The aim of this study was to describe nurse's palliative care competence areas in basic and specialized level in health care.

Methods: The data was collected with an electronic questionnaire containing open questions (n=10) from palliative care nurses (n=131) working at the basic and specialized level. The nurses answered the question "What every graduating nurse should know about the following areas" in 10 different categories. The data was analyzed with inductive content analysis.

Results: The most important results were: goals of care and advanced care planning, pain management and ethics. Goals of care and advanced care planning category included versatile theoretical information and preparation of an individual care plan in cooperation with the patient. Pain management category included management of pharmacological, non-pharmacological interventions and special techniques as well as strong expertise in evaluating the effect of pain management. Ethics category included sensitive ethical competence, understanding complexity of ethics and courage to act in conflict situations as a guardian of the patient's interest.

Conclusion: The study provides guidance to improve students' curriculum. The results demonstrate the importance of goals of care and advanced care planning, pain management and ethics in palliative nursing. Reaching excellence in palliative nursing needs evidence-based practice and development-oriented nursing leaders who implement palliative competences into integrated palliative care programs and services.

Funding received from government. Ethical approval was declared unnecessary by ethical committee.

OP-30_16

Effect of Early Physical Therapy Protocol on Shoulder Dysfunction After Neck Dissection in Oral Cancer Patients -A Randomised Control Trial

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Introduction: In oral cancer patients shoulder pain and dysfunction is common complication after neck dissection which results in scapular and glenohumeral muscle imbalances. Abnormal scapular biomechanics cause mechanical overload to shoulder joint complex resulting in pain, reduced function of shoulder joint and negatively affect quality of life (QoL).

Aim: To study the effect of early physical therapy protocol on shoulder dysfunction after neck dissection in oral cancer patients

Methods: Total 56 patients of oral cancer above 18 years, following neck dissection were studied. 23 patients in experimental group were assigned for early physical therapy protocol 5 times/week for four weeks and remaining 23 patients were assigned to control group. Shoulder range of motion (ROM) and EORTC QLQ-C30(European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30) were assessed on 1st week and 1month postoperatively. The programme included active shoulder and neck mobility exercises, active stretching exercises for neck and shoulder, scapular stabilization exercise.

Result: A significant p value was obtained ($p<0.05$) for shoulder abduction ROM and QoL after 4 weeks of rehabilitation in experimental group.

Conclusion: Early physical therapy protocol can improve shoulder function, shoulder abduction ROM, QoL of oral cancer patients after neck dissection.

OP-37_18

Development and Validation of a Questionnaire to Explore Preferences Of Patients, Family Caregivers and Kidney care Providers on Advance Care Planning in an End-Stage Kidney Disease Setting

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Introduction: Advance care planning (ACP) is a process that facilitates patients to express and record preferences regarding their future medical and personal care. Currently, there are no methods available to assess end-stage kidney disease patients', their family caregivers and kidney care providers' preferences regarding ACP in the Indian context.

Aim: This study aimed to develop and validate a English and Kannada version of questionnaire to assess awareness and knowledge of ACP among ESKD patients, caregivers, and health care providers.

Method: The questionnaire was developed from the published literature on ACP use in ESKD setting. Initial questionnaire was developed in English and was translated in Kannada. An expert panel consisting of nephrologists, palliative medicine physicians, ESKD patients and their family caregivers participated in the content validity of the ACP questionnaire using the Delphi process. The study was conducted between August 2021 to July 2022 at a tertiary care hospital in India. A validated questionnaire was administered to eligible 30 ESKD patients, 30 caregivers and 10- healthcare professionals. A retest was carried out one week after the first administration.

Result: The content validity ratio of each section of the questionnaire ranged from "0.6 to 1"and Cronbach's α value was 0.737 to 0.925. The intraclass correlation coefficient values for the test-retest of all three sections of this questionnaire varied from "0.879 to 0.972".

Conclusion: The questionnaire is a valid and reliable method for evaluating the preference and knowledge of ACP in ESKD patients, family caregivers, and kidney care providers.

OP-43_23

To Compare The Effect of Swallowing and Non Swallowing Exercises on Dysphagia In Post Operative Oral Cancer Individuals

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Introduction: Individuals with postoperative oral cancer are considered more prone to exhibiting signs and symptoms of dysphagia. Few studies on swallowing exercises have been proven to be effective on dysphasia individually. But there is limited evidence over these swallowing and non-swallowing exercises on post-operative oral cancer individuals who are diagnosed with dysphasia.

Aim: To study to compare the effect of swallowing and non-swallowing exercises on dysphagia in post-operative oral cancer individuals.

Methods: A comparative study was conducted in patients who were operated for oral cancer were randomly assigned to Group A (n=33) and Group B (n=33) where group A underwent non swallowing exercises and group B underwent swallowing exercises for 5 weeks, started 1 week after surgery. Pre and post assessment was taken and results were analysed with the help of modified water swallowing test and M.D Anderson dysphagia inventory.

Result: Modified water swallowing test and M.D Anderson dysphagia inventory significantly improved in both the groups with more significance in group A ($p<0.05$).

Conclusion: This study concluded that non swallowing exercises are more beneficial for the treatment of dysphagia in post-operative oral cancer individuals.

OP-44_27

Insight of Chronic Kidney Disease Patients on Hemodialysis Regarding the Goals of Care

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Introduction: The concept of hemodialysis was initially introduced as a precursor to renal transplant in earlier days. Later, as studies indicate, the percentage of people with chronic kidney disease (CKD) increased rapidly and hence, the goals of hemodialysis became blurred. Most of the patients are unclear about the treatment choices available and are unaware about the goals of care if dialysis is the feasible treatment option.

Aim: To assess the insight of CKD patients on hemodialysis, regarding the goals of care.

Methods: A cross sectional survey is being conducted on 100 patients with CKD who are receiving hemodialysis in the dialysis unit of a tertiary care hospital in India using a semi-structured questionnaire.

Results: The study is ongoing, and the analysis of the responses will be shared during the final presentation.

Conclusions: The findings of the study are likely to influence the way in which discussions and decisions on treatment options including hemodialysis for CKD patients are done in healthcare settings.

OP-52_25

The Effect of Proprioceptive Training Using Modified Trampoline versus Conventional Proprioceptive Training on Balance in Cancer Subjects with Chemotherapy Induced Peripheral neuropathy – A Comparative study

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Introduction: Chemotherapy Induced Peripheral Neuropathy (CIPN) is the common complication of Chemotherapy which are widely utilized for the effective treatment in cancer subjects which later results in nerve involvement, nerve damage & nerve pain. It is becoming growing problems which varies among the different classes of drugs. This weakens the reception, transmission, & response to stimuli consequently impairs one's tactile sensory perception which results into loss of balance in cancer subjects with CIPN. Hence, an important focus of rehabilitation for cancer patients with CIPN is the development of interventions to promote proprioception and balance.

Aim: To Improve the Balance in Cancer Subjects with CIPN by Comparing the Effect of Proprioceptive Training Using Modified Trampoline with Conventional Proprioceptive Training.

Method: The conducted study was an experimental comparative study consisting of colorectal cancer subjects who have received chemotherapy and experiencing symptoms of CIPN. Total 26 subjects were taken of more than 41 years of age and divided among Group Modified Trampoline Training & Group Conventional Proprioceptive Training as per the inclusion criteria. Study was conducted for 4 weeks for 3 days/ week by using BBS and 8-Foot Up and Go test before and after the intervention to assess balance.

Result: A significantly higher 8- Foot Up and Go test score was observed in CIPN subjects with Modified Trampoline Group ($p<0.05$).

Conclusion: The study concluded that Modified Trampoline Training is more effective to improve balance in subjects with CIPN as it not only improves the static balance but it also improves dynamic balance.

OP-57_29

Predictors of Death in Children's Palliative Care of a Low-Middle Income Country

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Introduction: Almost 1.2 million children at the end of life (EoL) worldwide are needing palliative care and 24% of them are in Southeast Asia where Philippines belong. However, there is scarcity of evidence on the estimate of Filipino children who need palliative care.

Objective: This is pilot study aims to estimate the number of children who would benefit from children's palliative care (CPC) in a tertiary pediatric government hospital.

Method: A retrospective study of patients' charts admitted in January and February 2020 was done using a needs assessment form containing two parts. First part excluded the charts that are not candidate for CPC based on diagnsosis, and the second part identified the clinical and demographic profiles. Data were analyzed by average, frequency, and multivariate logisic regression using Microsoft Excel and STATA version 15.

Results: It was found that 52% of the population requires palliative care based on their primary diagnosis. Sixty-one percent (61%) were males and 52% belonged to ages 1 to 9 years old. Eighty-four percent (84%) were admitted in Medical units while there is almost equal proportions between Surgical and Intensive Care units. Using the multivariate logistic regression, it was found that the age and the unit of admission were the significant independent predictors of death. Children less than 1 year old has 3 times the odds of dying in the hospital while those admitted in surgical or intensive care units had 2 times the odds of dying compared to children admitted in the medical units.

Conclusion: This pilot study was able to establish an estimate of Filipino children who need palliative care. Data gathered from this study will support further researches and action plans to improve the quality of service in CPC.

OP-59_36

Evaluation of "Ruma Abedona Hospice Magic Formula" in Treating Oral Candidiasis

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- **Title of Study:**

  Evaluation of "Ruma Abedona Hospice Magic Formula" in Treating Oral Candidiasis

- **Presentation Preference:**

  ORAL

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- **Specific Themed Category:**

  Broad Category- Oncology Palliative Medicine
  Subcategory- Symptom Management other than Pain

- **Material previously published or presented in part:**

  NO

Introduction: Oral Candidiasis is a common problem encountered in palliative care. Patients with suppressed immune system alongside factors like usage of antibiotics, anti-cholinergic drugs, corticosteroids, intake of oral and systemic chemotherapeutic drugs and radiation therapy are highly susceptible to develop Oral Candidiasis.

Aim and Objectives: To assess the efficacy of "Ruma Abedona Hospice (RAH) Magic Formula" in treating Oral Candidiasis.

Methods: We conducted a cross-sectional study on 77 patients who presented with Oral Candidiasis at our Palliative Care Hospice. We collected relevant data (according to RAH Oral Health Assessment Scale), assessed their symptom patterns and clinical signs. On admission and during their 1-4 days' stay at our Hospice, these patients received "RAH Magic Formula" (our own recipe mouth wash) for oral care. They were subsequently discharged, advised to continue oral care at home and kept on regular follow-up.

Results: Patients' receiving the "RAH Magic Formula" showed steady improvement in their Activities of Daily Living (ADLs). They had marked improvement in terms of dryness of mouth (in 70.8%), better oral pain control (in 64.7%), reduced halitosis (in 67.8%), and reduced dysphagia (in 64.2%). On subsequent visits, about 74% patients were observed to have a more than 50% reduction in their initial white patches, suggesting marked reduction of Oral Candidiasis.

Conclusion: The burden of symptoms of the oral cavity is not routinely assessed by the family members of the patients due to lack of awareness. Our study hence contributes effectively to the overall qualitative improvement of ADLs in such population.

OP-65_32

Cultural adaptation of Patient Health Questionnaire (PHQ)9 for use in Palliative care settings

Pallika, Neha Arora, Narinder Gautam, Anu Paul,
Tushti Bhardwaj

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- Theme: TRACK 3: Oncology Palliative Medicine
- Subtheme: Quality of Palliative Care

Background: PHQ9 in Indian settings is yet not very often used in palliative care with the Hindi speaking population. The Hindi version of PHQ9 is available but its cultural adaptation to the Hindi speaking population in North India receiving palliative care services is required to be tested. PHQ9 as a depression screening questionnaire may help to identify depression symptoms among cancer patients.

Aim: To examine the cultural equivalence of PHQ 9 Hindi for use with cancer patients receiving palliative care services in North India.

Methods: Based on standard methodology of Translation and adaptation of the scale, following process was used: (i) Two focused group discussions with 19 experts working in cancer palliative care setting (ii) Qualitative interviewing with 11 patients (iii) Research team review. All interviews were audio recorded, transcribed and item wise content analysis was conducted.

Results: A few difficult phrases in original PHQ9 were *'dilchaspi', 'avasadgrast'*, 'kam Urja', *'nakaam', 'parivar ko neecha dhikhana', 'ashthir'* which were changed to *'Kam Mann Lagna', 'Mann Dukhi hona', 'kamjori', 'saksham nahi hain', 'Parivar ko nirash karna', 'bechain' respectively.* Two items namely no.6 and 8 were changed to shorten the length for appropriately conveying the meaning.

Conclusion: Hindi language involves various dialects which changes from region to region bringing variations in understanding the meaning of the words. It is recommended that culturally equivalent scales are used in practice and research. PHQ9 is now culturally adapted for the Hindi speaking population in North India. PHQ9 will help early identify depressive symptoms. Psychometric testing of PHQ9 is underway.

OP-69_38

ABSTRACT FOR ORAL PRESENTATION

TRACK 2: RENAL PALLIATIVE MEDICINE

SUB-CATEGORY: QUALITY OF PALLIATIVE CARE

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Association of Family Rated Quality of Death With Stopping Dialysis and Receipt of End-of-Life Care.

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Introduction: Approximately one in every four patients receiving maintenance hemodialysis for end stage renal disease eventually stop treatment before death. There is a paucity of information on association of stopping dialysis and quality of end-of-life care.

Aim: To evaluate the association of stopping dialysis before death, receiving end of life care with family rated quality of death amongst end stage kidney disease patients receiving maintenance hemodialysis hospitalized in the ICU setting.

Design, Setting and Participants: This study was conducted at Kasturba Hospital Manipal and included data from end stage kidney disease patients on maintenance hemodialysis and who were hospitalized in the ICU, had stopped dialysis before death and received end-of-life care and died between January 1, 2020, to October 30, 2022. Out of 98 patients who died, 23 had stopped dialysis prior to death and received end-of-life care.

Exposure: Cessation of dialysis treatment before death and involvement of Palliative care department in end-of-life care.

Outcomes and Measures: Family rated quality of death with modified Quality of Death and Dying questionnaire conducted through telephonic interview by a single interviewer.

Results: The study analysis is ongoing and would conclude by November 30, 2022.

Conclusion and Relevance: This study survey aims to highlight the importance of shared decision-making regarding withdrawal of dialysis for end stage kidney disease patients on maintenance hemodialysis who are critically ill and the role of palliative care in providing such patients with high quality end-of-life care.

OP-70_39

Symptom Burden in Chronic Kidney Disease Patients Stage 4-5 in an Indian Tertiary Referral Hospital

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Introduction: The reported prevalence of CKD in India across different regions ranges from <1% to 17% while the estimated global prevalence is about 13.4%. There is also an increasing number of young patients with CKD in India due to a variety of reasons like low birth weight, nutritional deficiencies leading to low renal volume at birth and a lower eGFR. Consanguinity and genetic inbreeding also result in a higher incidence of congenital abnormalities of the kidney. Added to this is the growing incidence of hypertension and diabetes. With a large discrepancy in the availability of adequate care and screening tools, it is expected that a large population of CKD patients go untreated until recognised with an eGFR of <15mL/min/1.73m^2 by which point, patients are expected to have high symptom burden. Symptom burden in CKD patients is poorly studied and even more poorly treated in India.

Aim: To study the symptom burden in CKD patients, stage 4 and 5, who may or may not be undergoing haemodialysis.

Method: 500 in-patients with CKD stage 4 and 5, studied using IPOS Renal 2.0 (staff version)

Results: The outcome analysis of this study will be listed in terms of severity and impact on the patients' day to day activities.

Conclusion: This study is expected to add value to the inadequate data available for the same in India.

OP-71_145

The Cardiff University Commonwealth Scholaship Commission Distance Learning Students 2006-2022

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Introduction: The Commonwealth Scholarship Commission in the UK (CSC) provides around 800 awards for postgraduate study and professional development each year. The Cardiff University MSc in Palliative Medicine for Healthcare Professionals and educational partner organisation Karunashraya, Bangalore Hospice Trust have been in regular receipt of distance learning awards for South Asian students since 2006. The Department of Palliative Medicine and Supportive Care at Manipal Academy of Higher Education (MAHE) have recently joined this academic partnership.

Methods: The course team and our network of alumni in India provide support for students locally and are themselves supported by the CU academic team.

Results: In the period from 2006 to 2022, 106 scholarships have been awarded to fully fund students to study towards an MSc in Palliative Medicine from Cardiff University.

In a 2017 survey of alumni, on a scale of 0 - 100 (zero to high impact) the average impact of undertaking the Cardiff University MSc on their different roles was: - clinical role 82 (50-100); - teaching role 82 (30-100); - management role 68 (20-100) - and research role 74 (35-100). We are repeating this work and wish to present our findings at the IAPCON 2023 conference.

Conclusions: The Cardiff University MSC Programme, the Commonwealth Scholarship Commission and our partner organisations have made a very significant contribution to the development of palliative care in this region and alumni continue to hold leadership positions in national and international palliative care organisations, driving the development and sustainability of palliative care services in India.

OP-76_48

Virtual Training for the Integration of Palliative Care to Manage Patients with Respiratory Diseases- An Observational Study

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Introduction: Palliative care approach can alleviate suffering and enhance quality of life. Early integration of specialized palliative care can resolve the physical and psychosocial needs of patients with respiratory diseases and can provide relief from pain and other distressing symptoms.

Aim: To study the effectiveness of a virtual training program focused on integrating palliative care principles into pulmonology practice.

Methods: Modules covering management of respiratory symptoms was developed and delivered online. The course completion rates were calculated. A detailed end evaluation was done among the participants to know their confidence level in prescribing strong opioids, symptom management and effective communication before and after the training program.

Results: The virtual program was attended by 46 doctors involved in treating patients with respiratory diseases. The completion rate was found to be 78.2%. A paired t-test was run on a sample of 30 responses received to understand the mean difference between the scores obtained before and after the training. Mean difference in confidence was observed at 3.57 in prescribing oral or IV morphine, 3.03 in palliative management of respiratory symptoms, 2.53 in managing non-respiratory symptoms, 2.03 in effective communication, and 2.53 in bringing end of life care conversations which was statistically significant at p-<0.001.

Conclusion: The virtual training program shows improved confidence levels and can be an effective and affordable method for dissemination of knowledge to doctors for the early incorporation of palliative care in the respiratory disease trajectory.

OP-83_134

Analysis of Symptom Burden and Quality of Life in Patients Undergoing Haemodialysis At Tertiary Care Centre

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Introduction: Chronic kidney disease cases are an increasing trend in India. Such patients have a wide variety of symptoms. There are studies assessing psychological distress in such patients in other parts of the world, but no such assessment has been done in India.

Aim: This was a Cross-sectional study; for patients undergoing haemodialysis, to evaluate the symptom burden and to assess the impact of Psychological distress on Quality of life.

Methods: Patients attending Dialysis Unit, AIIMS, New Delhi; and receiving Dialysis were recruited for the study. The patient's demographic data was recorded in a predesigned proforma. Symptom burden was recorded using Dialysis Symptom Index Scale questionnaire (30 questions, Likert scale, 0-4), filled by the patient. Symptom burden and its impact on quality of life was assessed by the IPOS-renal [staff version] tool (11 questions), filled by the primary investigator.

Result: 22 patients completed the questionnaire. The most common symptoms that bothered the patients were fatigue, insomnia, headache, loss of appetite. Fatigue was the most common symptom (16/22), followed by insomnia (12/22).

Conclusion: Symptom burden is a strong predictor of reduced health-related quality of life and survival in patients with end stage renal disease. A holistic clinical picture of ESRD that includes multidimensional symptom assessment is warranted for better disease management and resource allocation.

OP-84_52

Acute Palliative Care Unit at a Government Tertiary Cancer Centre

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Introduction: Acute Palliative Care Units(APCUs) are dedicated in-patient units where the interdisciplinary palliative care teams assume primary responsibility to deliver comprehensive care that addresses the physical,emotional and spiritual domains of suffering for patients in severe distress. The MNJ Institute of Oncology and Regional Cancer Centre (MNJIORCC) is a 500 bedded sole tertiary public referral centre for the state of Telangana.The APCU at MNJIORCC, which is a 6 bedded unit, was started on August 10th , 2021.

Method: Data was collected from the register maintained at the APCU from a time period of 10/8/2021 to 31/10/2022 to evaluate the demographics,nature of admissions and their outcomes.

Result: During this time period a total of 532 patients were admitted of which 274(51.5%) were males and 258(48.5%) were females.Patient presented with a multitude of symptoms with the most common being pain-345 patients(64.8%), followed by dyspnoea-111 patients (20.8%). Nearly 17 %(90 patients) were admitted at the APCU for EOLC. Of the total admissions, 110 patients(20.6%) passed away, while 47 patients(8.8%) were shifted to hospice. 43 patients(8.0%) who were admitted at APCU were able to continue active treatment for their disease once their symptoms were under control.

Conclusion: An APCU forms an essential part of the Cancer care programme and provides an extra layer of support for patient receiving concurrent treatment.

OP-89_55

Early Integration of Point of Care Ultrasound in Oncopalliative Care

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Introduction: POCUS (Point-of-Care Ultrasound) is the bedside Ultrasound done by the treating physician (non-radiology physician) to evaluate their clinical findings or as a guidance for interventional procedures. Being a palliative physician, we focus on symptom relief rather than definitive cure. The benefit from POCUS is significant in oncopalliative patients as it is time saving, non-invasive, affordable and also minimising interdepartmental trips, hospital stay, or any procedure related complications. So, an early integration of a real-time imaging tool like Ultrasound along with routine clinical assessment will enhance the diagnostic skills of clinician and helps in making further management plan more confidently.

Aim: To evaluate the changes in the management plans of patients with thoracoabdominopelvic or breast malignancy by incorporating POCUS into routine assessment.

Methods: Prospective cross-sectional study.

Study setting: Palliative care ward in Tertiary care hospital, India

1. Dr B.R.A. Institute- Rotary Cancer Hospital (IRCH) – AIIMS, New Delhi. 2. National Cancer Institute (NCI) -AIIMS, Jhajjar.

Patients with primary thoracoabdominopelvic or breast malignancy irrespective of the disease staging or the presenting symptom during admission in our ward, along with the routine clinical examination will undergo a POCUS screening of Thorax abdomen and pelvis, B/L 2-point DVT screening (Common Femoral Vein, popliteal vein) B/L Optic Nerve Sheath diameter (ONSD).

Results & Conclusion: Data is under evaluation. Expected outcome is to asses the role of early integration of POCUS in our study population, and type of interventions required for their symptom management.

OP-92_58

Parents Perspective of Home Based Paediatric Palliative Care Services – An Observational Study

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Introduction: Families of children under palliative care services experience a lot of stress. One of the goals in Paediatric Palliative Care is to improve the Quality of Life not only for the child but also their family's. It is well documented that home is the best place for providing palliative care for children as it allows the child to be in familiar atmosphere of home, the siblings can be taken care of, there is support of the relatives and the bread winner of the family can continue working. But home-based palliative care services have its own challenges like lack of specialist care on emergency basis, incoordination amongst the team, lack of skilled and experienced staff. It is very important to understand the parent's perspectives so that palliative care services can be aligned accordingly for better outcomes.

Aim: The objective of the study is to systematically review the parent's views on the various aspects of home based paediatric palliative care services being provided and understand if there are any lacunae so that we can come up with recommendations to improve.

Methodology: There are 203 children registered under Pain Relief and Palliative Care Services (PRPCS) Hyderabad. They are children with either oncology or non-oncological conditions who have been discharged from either MNJ Cancer Institute or Niloufer Paediatric Hospital. Some of them are directly registered too. These children are categorised into Low Priority, Medium Priority or High Priority basis of their symptoms or diagnosis. They are under the care of a home care team consisting of a nurse, counsellor and physiotherapist. For high priority cases a doctor also accompanies the team. For the purpose of the study, the doctor who is going to be called the observer, accompanied with the team randomly without the preference to High Priority children. On reaching the residence the Observer interacted with the parents and enquired about their opinion on the services being provided and what can be done to improve the home based paediatric palliative care services. The points mentioned by the parents were segregated into themes. The observer has interacted with a total of 21 families so far. Of the 21 children, 9 were suffering from cancer and 12 were suffering from non-cancer conditions. There were 8 girls and 13 boys. Among the children with cancer 2 were in EOL care and in non-cancer group 1 was in EOL care. The responses were grouped as 11 positive themes and 2 negative themes. They are mentioned in the tabular column below:

Positive responses

SI No	Theme	No. of families	Remarks
1	Time and service	4	It is a unique service and it made the child feel special.
2	Logistics	21	It was very comfortable as they could continue working, schooling of siblings was not affected
3	Saviour	1	During covid pandemic the home based PPC was a saviour
4	Gastronomic wishes	1	Child could get to eat whatever he wanted
5	Happy sibling – Happy Child	3	Child was happy to stay with the siblings at home
6	Doubt free when not in hurry	6	They could get information about the child's condition and could manage the child properly
7	Diversion	2	They expressed that the visit of the PPC team was a diversion for the child
8	Resourceful	3	When they were not having funds, the necessary medicines were provided by the PPC team
9	Gratitude for improvement	2	Due to regular visits by the physiotherapist, there was a significant improvement in the child's condition
10	Special touch	1	They wouldn't have got 100% attention in the hospital like they get in the PPC
11	Safe and secure	1	The PPC team was a phone call away so they felt very safe

Negative Responses

1	Medicine availability	2	The PPC team should note all the medicines needed until the next visit and ensure that they are provided
2	Frequency of visits	2	Increase the number of visits by the team and preferably with the doctor each time

The study is still on going and will be concluded by Dec 31st 2022. The final analysis and conclusions shall be derived by January 2023.

OP-95_64

Integrating Body Mind Wellness BMW through Blue light visualization Cognitive technique

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WHO defines health as a complete state of physical, mental and social wellbeing and not merely the absence of disease or infirmity.

Aim: To understand the experience of palliative care patients participating in an experimental blue light therapy and to integrate the Body mind wellness BMW in palliative patients and to explore if this experience can improve well-being.

Method: 25 patients with any chronic disease admitted in DRMC between July 22 to Dec 22 were enrolled to take part in a daily blue light therapy session along with their other treatment. patients were given a verbal and oral presentation. patients were given a most comfortable position and were encouraged to look at blue fluorescent tube light for 10 seconds and them asked them to close eyes and ask them to visualize that this blue light is entering from outside the body to inside of chest, into the region of heart, near the left nipple and then assuming it mixing with blood and travel throughout the body including the diseased part. Participants were asked to do this for 5 minutes.

Results: This technique accepted by 97% of people, it took a median of 3 sessions to allow majority of patients to practice optimally. The behavioral changes were noticed after a week as: development of wellness feelings (76%), improvement in mental peace (65%), acceptance of disease (95%), more assertive and emotionally controlled (78%)

Conclusions: This research showed blue light technique is an easily taught, executed and effective body, mind technique in a palliative care center.

OP-104_73

Psychological Distress and Quality of Life in Non-Small Cell Lung Cancer Patients Receiving Chemotherapy: - A Prospective Observational Study

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Introduction: In twentieth century, Lung cancer is the leading cause of cancer death. And amongst the death due to Lung cancer NSCLC contributes 80-85 %. Approximately in 40 % cases the disease gets metastasised to an advanced stage at presentation. Hence, in majority of cases cytotoxic chemotherapy is the management of choice. But those therapies have a strong side effect profile, like, fatigue, LOA, LOW, mucositis,esophagitis,neutropenia, sepsis, pain, bodily disfiguration, hopelessness, anxiety, depression. All collectively contributes to psychological distress. Above all the financial burden of the expensive treatment, loss of job, physical as well as financial dependence due to the disease, sex life disturbances have a huge impact on mental health, hence on the quality of life of the patient.

Aim: To address the psychological distress and its impact on QoL in NSCLC patients taking chemotherapy in Indian set up.

Methodology: Study Design: - a prospective observational study.

Study setting: AIIMS, New Delhi and NCI, Jhajjar, Hary

Study participants: Patients with pathologically confirmed NSCLC enrolled for chemotherapy.

Study Duration: September 2021 to February 2023

Sample size: Convenience sampling. Tools used-socio demographic proforma, semi structure proforma for disease status and symptoms, ECOG scale, DASS 21 , WHOQOL BREF scale,

Results And Conclusion: Data collection is under process. Results will be processed at the completion of the study.

OP-105_74

Chemical Pleurodesis with Povidone-Iodine in Patients Having Malignant Pleural Effusion

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Introduction: Pleurodesis is one of the common methods to manage malignant pleural effusion(MPE) Various agents are used over past 100 years to carry out chemical pleurodesis. Based on local availability, high efficacy and safety profile we chose povidone-iodine in our study.

Aims: To study usefulness, effectiveness, safety and complications.of Povidone-iodine in chemical pleurodesis,

Methods: It is prospective analytical study, conducted over period of nine months in our hospital. Patients were included in the study as per inclusion & exclusion criteria. Pleurodesis was carried out in priorly inserted Intercostal drainage with help of povidone-iodine, normal saline and lignocaine. ICD was clamped for next 2 hours and removed when ICD output was <100cc. patients were observed for 2 hours for vitals and other complications. patients were followed up after 1 week, 1 month and 3 months to see the response of pleurodesis in terms of reaacumulation of fluid and need for further intervention.

Results: Seventeen patients were included in the study. Total 94% patients had complete response to pleurodesis, 6% patients had partial response and no patients reported failure. After pleurodesis, 17% and 35% of patients reported chest pain and mild burning sensation respectively. But no fatal complications.

Conclusions: The pleurodesis with povidone-iodine is useful procedure for MPE; povidone-iodine is a cheap, easily available, efficacious, safe sclerosing agent.

OP-111_98

Grief And Coping Mechanisms in Health Care Professionals Working with Terminally Ill Patients: A Pilot Study

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Introduction: Grief is a natural response that is experienced by loss of a loved one. Most of the time the focus is on immediate family members, whereas less attention is given to health care professionals who also undergo grief in the process of providing care to the patients during their last days.

Aim: The aim of this pilot study is to explore the relationship between grief and associated coping mechanisms used by health care professionals working in end-of-life care.

Method: A correlational study was used to identify the relationship between grief and different coping mechanisms used by health care professionals to deal with the grief. A purposive sampling technique was used to gather the data (N=60). This study was conducted using the Brief Cope Scale (BCS) and Texas Inventory of Grief (TRIG) were administered. The obtained data were scored and statistically analysed using SPSS software.

Results: The results showed a significant correlation between grief and ways of coping with it. This implies that various coping strategies (venting, humour, emotional support, religion, and acceptance) were adopted by the healthcare professionals to cope with their grief.

Conclusion: This study concluded that health professionals engage in variety of coping mechanisms to deal with the grief they experience in their work setting. A supportive work environment and regular screening for complicated grief should be carried out for professionals closely working with dying patients. Practicing self-care and regular debriefing sessions for healthcare providers will help them to overcome the grief they experience due to a patient's death.

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OP-112_80

Exploring Pediatric Palliative Care for Neurodevelopment disorders in Nepal: A scoping review

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Introduction: Nepal is in the early stages of development of pediatric palliative care which is mostly focused on malignancy. Palliative care for children with life limiting developmental disorders including cerebral palsy, autism spectrum disorder (ASD), intellectual disability (ID), Down's syndrome and muscular dystrophy have not featured prominently. Nepal, like other low-middle income countries has a high burden of cerebral palsy. An integrated pediatric developmental disorder and palliative care service at Green Pastures Hospital (GPH) is being established.

Aim: To explore the need for palliative care for children with neurodevelopmental disorders in Nepal.

Method: Scoping review of relevant articles and data from GPH Developmental Pediatric Clinic (GPHDPC).

Result: The few pediatric palliative care studies published report on children living with and dying from malignant disease; many facing delays in starting palliative care. A modelling study of 2012 data predicted that 484 children dying each year in Nepal required palliative care, with cancer accounting for under 25%. Developmental disorders and congenital abnormalities accounted for more than 75%. No studies on palliative care for children with developmental disorders in Nepal have been reported. 170 children attended GPHDPC in one year between July 2021 and July 2022 including: cerebral palsy 60, ASD 20, ID 18, seizure disorder 17, Down's syndrome 9, muscular dystrophy 6 and 39 other conditions including multiple diagnoses. An estimated 45% had palliative care needs.

Conclusion: Whilst little has been published, data from GPHDPC suggest a substantial need for palliative care in children with development disorders and their families in Nepal.

OP-114_124

Establishment of Neuro-palliative care services in a tertiary hospital: preliminary findings

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Introduction: Patients with chronic, progressive neurodegenerative disorders experience distressing symptoms and have changing needs associated with the illness progression. Neuropalliative care is emerging as a subspecialty and different context specific service delivery models for those who require services need to be explored.

Aim: To describe the profile of patients and challenges faced in a newly established neurology palliative care clinic.

Methods: We describe the preliminary findings from the establishment of a dedicated interdisciplinary, neuro-palliative care clinic in a tertiary care Neuropsychiatry in South India. The database of the first 500 patients who were referred during the first six months of the establishment and who completed the assessment are analysed. Qualitative interviews were conducted with consenting patients-caregiver dyads. The participants were assessed on socio-demographic proforma, Functional Independence Measure (FIM) and Integrated Palliative care outcome scale (IPOS), as well as interview schedule.

Results: 509 patients were referred for the specialist neuro palliative care during the study period. Neuromuscular disorders (Mainly ALS) were most commonly referred followed by advanced dementia and movement disorders. Reasons included communication and psychosocial support, complex symptom management, symptom-based care giving support. The perceived needs included the need for accurate and sensitive communication of information, symptom management, especially of distress symptoms, and support as the disease progresses.

Conclusion: Detailed profile and challenges faced, including developing a strategy for continued development, integrating services with specialities in neurology, improving primary palliative care knowledge and skills, building effective networks are presented.

OP-115_81

Scoping study to mandate screening of depression in palliative care policies in Low and Middle-Income Countries

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Introduction: Depression among palliative care patients is highly prevalent yet under-detected worldwide. Majority of these patients reside in LMICs where studies have amplified the need for depression screening.

Aim: To conduct a scoping review to understand the inclusion of screening for depression in palliative care patients in the health policies of LMICs.

Methods: Countries from LMICs were selected based on criteria to have a stand-alone Mental health policy and a Palliative care policy or palliative care mentioned in the National Health Policy. Ministry of health websites was scrutinized and also through a PubMed search, information was retrieved. Key influencing reports of the WHO and Lancet Commission were also reviewed.

Results: 135 policies and supporting documents were included in the selected 46 LMICs. 22 countries had a stand-alone palliative care policy of which 3 countries were in the advanced stage of integration in health service provision, with community-based home care, funding, trained workforce, and opioid availability. None of the policy documents emphasized mental health aspects in palliative care, and in the respective mental health policy, there was no reference to palliative care patients.

Conclusion: Untreated depression exacerbates illness-related suffering in palliative care patients and adversely affects treatment outcomes and quality of life. Thus there is an urgent need to incorporate screening for depression in palliative care patients in relevant national health policies.

OP-120_88

Impact of Happy Feet Home Foundation (HFH) work in Palliative Care for non-cancer illness

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Happy Feet Home

Introduction: HFH is a palliative care center in Mumbai working with children and young adults who are infected / affected with life threatening and/or life limiting illnesses like HIV, Thalassemia Major and Cancer. The children and young adults come from low economic background.124 children are registered for the holistic day care services. None of these children have cancer.

Aim: To ensure the holistic day care services improves quality of life for the children.

Methods: Once registered with HFH, nutritional and medical needs are prioritized. Psychological assistance is provided to all to help boost their confidence, deal with emotional concerns and set goals. Support is then provided by choosing appropriate courses and trainings for them and it continues till they are financially independent.

Results: 1. 66.67% of HFH children are studying either in college or school. 2. 6.5 % of the children are learning basic literacy. 3. 17.89 % of the children are in some vocational course and will soon be financially independent. 4. 8.94% of the children are financially independent. 5. As an example of improvement in quality of life – one family with two HIV positive children had the grandmother's pension of Rs,2100/- per month as the only income source. With HFH support, the elder child, now 24years old, supports the family with an income is Rs.30,000/- a month.

Conclusion: Providing holistic and equitable growth opportunities to children with life threatening or limiting illness, improves their overall well-being.

OP-123_102

Advocacy on the integration of Palliative care into the Undergraduate Nursing Curriculum – an untiring Journey

Dr A .Latha

Dr A .Latha, Lt Col. Lovely Antony, Anu Savio Thelly, Lt Alice Stella Virginia

Introduction: Palliative care has become an area of special expertise within medicine, nursing and other disciplines. Nevertheless, advances in palliative care have not yet been integrated effectively into the standard curriculum in nursing sciences. This paper is about the advocacy efforts taken by the palliative care community in India to integrate palliative care into the undergraduate (UG) nursing curriculum by the Indian Nursing Council (INC).

Methods: Multiple advocacy initiatives have been underway for the last 15 years. The major milestones are: 2006: The Government of India formed a committee involving experts in palliative care from various parts of the country to create a National Policy for Palliative Care.2006-2007: The initial attempts to integrate palliative care into the UG medical and nursing curriculum was started. 2012: With the participation of INC, the Ministry of Health & Family Welfare declared the National Strategy for Palliative Care. An essential aspect of this strategy was the appropriate inclusion of palliative care in the UG nursing curriculum. 2013: Pallium India spearheaded drafting a palliative care curriculum for the UG Nursing course in collaboration with WHOCC, Calicut and other palliative care organisations in the country. 2013-2022: Multiple advocacy initiatives by different palliative care organisations in India. 2018: Integration of palliative care to UG, Postgraduate (PG) modules at Kasturba Gandhi College of Nursing, Puducherry, South India in collaboration with Pallium India. 2022 Feb: INC announced the integration of palliative care to 2nd year BSc Nursing as X 20 hours mandatory module 2022, May: INC published the competency and subcomponents 2022, June: Pallium India started the preparation of modules with a national team of palliative care nurses 2022, Dec: Proposed completion of modules.

Conclusion: India is one of the very few countries with palliative care being integrated into the UG Nursing curriculum Dr.A.Latha Tutor, College of Nursing. AIIMS Jodhpur.

OP-129_97

Clinical Audit of Inpatients using Nepali Palliative Care Outcome Scale (NPOS)

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Introduction: Nepali Palliative Care Outcome Scale (NPOS) was developed using the standard process proposed by the POS developers. NPOS consists of 19 items covering: symptoms, quality of life and care; information needs; family caring burden, on a 5-point scale (0=no problem, 4=most severe problem). NPOS use in clinical practice has not previously been reported.

Aims: To audit effectiveness of palliative care in inpatient unit in Nepal using NPOS.

Method: NPOS administered to inpatients on admission (T1) and after 1 week or at discharge (T2).

Results: 106 patients completed NPOS at T1 and T2 including: CVA 39; Cancer 12; Burns 5; post-covid 4; brain injury 3. The T1 mean total score was 38/76 (range7-73) reducing to 18/76 (range1-35) at T2. The score increased in 3 patients (range3-6). 58/106(55%) had a T1 score >37 (mean 49 range38-73) reducing by mean 28(58%) (range16-52) at T2. 71/106(67%) had pain at T1 and 69/106(65%) at T2 (36 improved, 13 worsened). 8/106(8%) had severe or very severe pain (score 3-4) at T1; all improved by T2. The highest T1 scores were for poor mobility, lack of satisfaction with life and lack of peace. Mobility improved more than satisfaction or peace. The largest improvement was for constipation where average scores decreased 41%.

Conclusion: NPOS seems an effective tool for auditing outcomes in inpatient palliative care. It uncovered high levels of suffering and significant improvement within one week. NPOS is enabling clinical teams to critically assess outcomes. Formal validation of NPOS is planned.

OP-134_106

Characteristics of a Pediatric Palliative Hospice Program in Kuwait: Advocacy through numbers

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Introduction: Bayt Abdullah Children's Hospice (BACCH) is the first of its kind in the Gulf region providing Pediatric Palliative Care (PPC) in Kuwait. The experiences learnt can be a guiding light for those planning services in PPC.

Objectives: • Understanding the most common and frequent diagnoses seen in a Pediatric Palliative Care setting helps in having an objective measure of services required and provided. • The data can be used to advocate for the children as well as identify the gaps to strengthen referral systems. • A detailed review of the case load in the past 10 years including. This study shall describe the characteristics of and services delivered to all children in the Pediatric Palliative Care program from 2012-2022.

Methods: A retrospective review of all the current case load is done to collect the demographics, diagnostic groups, duration of access to PPC services, mortality data and location of death.

Results: The study cohort included 79 children on the current case load. The majority of diagnoses belonged to Genetic conditions (34%), neuromuscular conditions (19%), central nervous systems conditions (18%) and oncology (14%). Further data points to be analyzed yet.

Conclusions: • Diagnostic groups help us quantify the nature and extent of PPC services used and is particularly helpful in developing further programs like BACCH. • The data also helps in targeting and building specific competencies of the clinical and psychosocial PPC programs. • The numbers when different from global trends might point to different PPC needs based on the region and also specialties that might need more awareness and integration of PPC.

OP-134_214

An Innovative & Endorsed Model of Pediatric Palliative Care Training – "Hybrid" Fellowship

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4. Dr Gayatri Palat, Head of the Department, MNJIO & RCC, Hyderabad

Introduction: Palliative care (PC) is an important component of care for children with cancer and other life-limiting conditions. Globally, 98% of children needing PC live in low- or middle-income countries, where access is often limited. Training opportunities for pediatricians are essential to improve access to PC in these settings.

Aim: To describe the development and implementation of a 1-year "Hybrid" Pediatric Palliative Care (PPC) Fellowship, combining clinical and online learning to train future specialist leaders in PPC.

Methods: The Hybrid fellowship was developed through the existing partnership between TWCC (Canadian NGO) and the Hyderabad Centre for Palliative Care. A leadership team of PPC experts, developed the fellowship after a review of literature and educational materials.

Results: The fellowship includes formal teaching, scholarly project, clinical rotations, mentorship, and regular trainee assessments. Teaching includes online classes, with focus on case-based learning and leadership skills. Research and Quality Improvement training is provided, and fellows complete a scholarly project. Four months of clinical rotations PC are conducted, including 2 months at a regional center of PPC excellence (Hyderabad). A mentorship program provides additional support, continuing beyond the fellowship through Early Career mentorship Group. Trainees' progression towards program competencies is assessed through written and observed standardized clinical examinations. Six fellows have completed the "Hybrid" fellowship, and have gone on to lead and develop new PPC programs. The program has obtained endorsement from the Royal College of Pediatrics and Child Health (UK). More than 30 regional and international PPC experts contribute as faculty.

Conclusions: Hybrid PPC Fellowship is an innovative model to increase access to specialist PPC training in resource-limited settings.

OP-136_146

Referral to Palliative Care Physician or Nurse and End-of-Life Conversations About Goals of Care Reduce The Intensity of End-of-Life Care in Children with Poor Prognosis Cancer – Interim Results of Inpog-Pall-18-01

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Introduction: Palliative care (PC) reduces inappropriate use of high-intensity care at the end-of-life (EOL) in high-income countries, but there is very limited data on PC provision for children with cancer who die in India.

Aim: To describe EOLC patterns for children with poor prognostic cancer (advanced/refractory/non-curable) who died at health facilities/at home (community-based PC) in India from 2017 to 2021.

Methods: Multicentric observational retrospective InPOG study to analyse the association between communication about goals-of-care and accessibility to specialized PC services with intensity of life-sustaining therapy (CPR, intubation/mechanical ventilation, dialysis, parenteral nutrition, inotropes, terminal ICU admission) at the EOL.

Results: 284 children from 13 centres, of which 10 had institutional PC services, died in hospital ward (55%), ICU (31%), hospice (9%) and home (6%). 40% saw a PC physician/nurse, 34% a psychosocial professional, while 49% met neither one. Conversations with families were documented in 195. In 115 families, communication was restricted to poor/grave prognosis. Goals-of-care discussion in the last 7 days was documented in 77 cases and was associated with less high-intensity EOLC in the last 2 days of life (43% vs. 72%, p<0.001). Less high-intense EOLC was associated with involvement of a PC physician/nurse (32% vs. 71%, p<0.001) or psychosocial professional (38% vs. 63%, p<0.001) in the last 2 days of life. Goals-of-care discussion and PC physician/nurse were independent factors for less intense EOLC.

Conclusion: Intervention of specialized PC physician/nurse and communication about goals of care at the EOL result in less high-intensity EOLC for children with poor prognostic cancer.

OP-137_110

Attitude of Nursing Students towards death and dying

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Introduction: Nursing students are prepared to care for patients in their entire continuum of life including during death and dying. Attitude towards death and dying are concepts which influence quality of end of life care.

Aim: The purpose of this study is to measure the attitude of nursing students towards death and dying and find any association of attitude to any student related characteristics.

Methods: A descriptive cross sectional study is conducted on 200 nursing students who are studying in three nursing colleges of Bangalore. After obtaining ethical clearance and administrative permission, data collection will be done. Written informed consent will be obtained from students who are willing to participate in the study. The tool includes demographic data as well as Death Attitude Profile –Revised and Frommelt Attitude towards care of Dying (FATCOD-B) scale.

Results: Both descriptive and inferential statistics will be used to analyze the data. The demographic characteristics will be described using measures of central tendency. The association of attitude with several variables including demographic and educational variables will be measured using chi square test.

Conclusion: This is an ongoing study which will be completed shortly. The attitude of nursing students to death and dying as well as various factors influencing the attitude will be studied.

OP-139_116

Palliative Care Needs of Patients with Life-Limiting Illnesses Presenting to The Emergency Department

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Introduction: Emergency department is a medical treatment facility where immediate and acute care is provided to patients who present without any prior appointment. Thus, emergency departments are important entry points to the healthcare system. Palliative care initiation in ED, may result in improvement of QoL. Being the gateway to hospitalization, the emergency department is a favourable space to initiate palliative care. The identification of patients at high risk for poor outcomes may allow for earlier palliative care and prevent futile interventions. Patients' autonomy can be respected in such a scenario and they will have the means to make informed decisions about future treatment options and end-of-life care.

Aim: To assess the palliative care needs of patients with life-limiting illnesses presenting to the emergency department.

Method: Prospective observational study. Unbiased convenience sampling will be done. The study will be conducted in the emergency department of AIIMS, New Delhi and NCI, Jhajjar.

Tool used: NAT-PD

Inclusion Criteria: Age > 18 years. Patients with chronic life-limiting illness not responding to curative treatment. • Terminal Cancer. • COPD - GOLD grade 4. • Heart failure - NYHA functional class IV. • Neurodegenerative diseases. • CLD - MELD score >40. • CKD - stage 5.

Results and conclusion: Data under evaluation. The data might prove helpful in providing integrated palliative care services to patients presenting to the Emergency department. Will be submitting the interim report of the study.

OP-140_168

Assessment of Insomnia, Depression and Anxiety in newly diagnosed lung cancer patients

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Introduction: Lung cancer being the 2nd most common cancer that needs to be evaluated from early stage of diagnosis. Patient not only suffers from physical distress but also from mental distress like insomnia, depression, anxiety etc. It is observed Insomnia(56%), depression(16-26%) and anxiety(30-35%) in Lung cancer patients. In western countries, mental health is given outmost importance and various studies has also been conducted but in India only few studies has combination of these , certainly a missing link in literature and needs to be addressed

Aim: Assessment of Insomnia , Depression and Anxiety and its effect on the quality of life in newly diagnosed Lung cancer patients presenting at Pain and Palliative care unit and Lung cancer clinic at DR.BRAIRCH, AIIMS, New Delhi, India

Methods: It is a Prospective Observational study , random sampling to be done of sample size 204 including the patients (male and female) with newly diagnosed Lung cancer, age group of 18-60years and able to communicate in English or Hindi.

Results: To be discussed at the time of presentation

Conclusion: To be discussed at the time of presentation.

OP-144_120

Prospective observational study of Symptom prevalence in actively dying cancer patients at a tertiary cancer hospital

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Introduction: Actively dying is defined as, " hours or days preceding imminent death during which time the patient's physiologic functions wane". As death approaches, patients experience progressive functional decline, worsening symptom burden and may require more aggressive palliation. There have been retrospective analysis of case reports in the western population but not many studies in our country that have explored the dynamic symptom burden in actively dying cancer patients

Aim: The aim is to prospectively evaluate the patient's physical symptom burden in the actively dying phase.

Methods: This is a prospective study in which 66 actively dying cancer patients admitted in Palliative care ward were recruited. Their symptom burden was evaluated using Edmonton symptom assessment scale (ESAS 0-10) along with demographic data & most distressing symptoms at the time of death. Data will be analyzed using SPSS 25.0. The study is ongoing.

Results: The median age of the patients was 48.9(SD 20.06). The most frequent cancer diagnoses were GI(19.6%) and Lung (15.2%). The maximum symptom burdens noted were shortness of breath (86%), decreased appetite (63%),fatigue (59%), constipation and agitation (28%). Shortness of breath being the most distressing symptom in (78%) of the study population

Conclusion: The study highlights the adequacy of effective symptom control and provide better quality of life during the last hours. Shortness of breath being the most distressful symptom followed by decreased appetite & fatigue. These data are important for healthcare professionals in understanding the awareness of patient symptoms & areas of unmet need among terminally ill cancer patients

Ref:

1. D, Nooruddin Z, Didwaniya N, Dev R, Cruz MDL, Kim SH, *et al.* Concepts and Definitions for "Actively Dying," "End of Life," "Terminally Ill," "Terminal Care," and "Transition of Care": A Systematic Review. J Pain Symptom Manage. 2014 Jan 1;47(1):77–89.
2. Kutner JS, Kassner CT, Nowels DE. Symptom Burden at the End of Life: Hospice Providers' Perceptions. J Pain Symptom Manage. 2001 Jun 1;21(6):473–80.
3. Morita T, Tsunoda J, Inoue S, Chihara S. Contributing Factors to Physical Symptoms in Terminally-Ill Cancer Patients. J Pain Symptom Manage. 1999 Nov 1;18(5):338–46.
4. Steindal SA, Ranhoff AH, Bredal IS, Sørbye LW, Lerdal A. Last three days of life in the hospital: a comparison of symptoms, signs and treatments in the young old and the oldest old patients using the Resident Assessment Instrument for Palliative Care. Int J Older People Nurs. 2013;8(3):199–206.

OP-149_138

"Primary Caregivers Stress assessment in Home Based Palliative Care at Jodhpur"

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Background: The main aim of palliative care is to improve the quality of life of chronically ill patients and address primary caregivers' stress. It is a known fact that during chronic illness, primary caregivers play a significant role in taking care of patients. Thus it is obligatory to address their stress and wellbeing.

Aim: To evaluate the stress of primary caregivers of palliative care patients who were registered for home based palliative care services in Jodhpur.

Methodology: In a cross sectional study, caregivers were enrolled after written consent. The study was conducted during April 2022 - Sep 2022. The Caregivers stress assessment questionnaire was used to assess their stress level during initial visit. After 3 months, a second assessment was done. In between, the home care team visited the patients and caregivers every fortnight or as and when needed by the patient. Individual and family counseling were provided along with nursing care to patients during these visits.

Result: A total of 67 primary caregivers participated in the study. The mean stress score at initial visit was 30.5 ± 5.12. At the end of 3 months, the mean score was 21.5 ± 5.88 [$p<0.005$].

Conclusion: This study shows that there is a significant reduction in post intervention stress level of caregivers. Thus analyzing stress during home care services has great value for primary caregivers.

OP-154_135

A Qualitative Exploration of Family Caregiving in Advanced Wilsons Disease

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Introduction: Wilson's disease is a rare disease that occurs due to abnormal copper metabolism. Advanced illness causes several multisystem illness and impacts the life of patients and their caregivers.

Aim: The purpose of this study is to explore the experiences of family caregivers of patients with advanced Wilson's disease.

Methods: Families of patients with advanced Wilsons Disease will be visited by the palliative care team as a part of the home visit program of palliative care services. Families that cannot be visited will be interviewed over phone. After obtaining consent, interview will be conducted with the primary caregiver of the patient based on a semi structured questionnaire. Interviews will be conducted in their language, translated to English and will be transcribed. Based on Braun and Clarkes thematic analysis, themes will be derived after repeated reading of the verbatim and condensing of the codes, by two researchers. Families will be included in the study until data saturation.

Results: The study is ongoing. The initial results reveal themes including 'impaired family process', ' concern about reversed role of older parents ' and 'fear of disease affecting the siblings'

Conclusion: Advanced Wilson's disease being a progressive disorder involving multiple symptoms, families caregiving is often demanding and challenging. In addition to the regular caregiving concerns related to progressive illness, the apprehensions of the family is compounded due to the inheritability of the illness.

OP-157_140

Financial Toxicity of Hematological Malignancies in India- A systematic Review

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Introduction and Aim: Financial toxicity includes the detrimental effects of out-of-pocket (OOP) expenditure and lost productivity of patient or the caregiver. Hematological malignancies are associated with a unique financial challenge from cost of diagnosis to treatment regimes, from some requiring long inpatient management to some requiring novel therapies like stem cell transfer (SCT) to Chimeric Antigen Receptor (CAR) T-cell. Globally evidence has shown financial toxicity of hematological malignancy significantly affecting survival and quality of life.

Methods: The authors performed a systematic review where financial toxicity of hematological malignancies was studied in India in exclusivity or along with other cancers. A search strategy with data specific keywords and phrases was used on multiple databases. We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations.

Results: Most factors affecting financial toxicity included household income, type of health-care facility used, stage of disease, area of residence, age at the time of diagnosis, recurrent cancer, educational status, insurance coverage and treatment modality. Two studies highlighted a combined 67% (two out of every three household) of patients compelled to borrow money for treatment. Our analysis also highlights the urban and rural divide with almost double OOP in the latter group

Conclusions: This study highlights the need to mitigate these challenges and the need for strategic decentralization, rural access to advanced diagnostics and treatment, nationwide implementation of health insurance schemes and the need for government-community participation to reduce the OOP expenditure in India.

OP-158_139

Caregiver burnout *and care management of patients with Amyotrophic Lateral Sclerosis (ALS): A cross sectional study*

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Background: Amyotrophic lateral sclerosis (ALS) is an idiopathic and fatal neurodegenerative disease affecting the upper and lower motor neurons and a rapidly progressing disease; Caring for a person with ALS can be extremely challenging. The Caregiver burnout is a state of physical, emotional, and mental exhaustion and distress that may include depression, agony, anxiety, and so forth that also may affect the care giver involvement in care management.

Aim: This study aims to examine the association between the caregiver burden and caregiver involvement in care management of patients with ALS.

Methodology: *A hospital based study conducted among patients with ALS receiving treatment in the department of Neurology a tertiary care center for neuropsychiatry in South India. Thirty consecutive patients with the diagnosis of ALS are purposively selected. The patients are assessed on their clinical profile and the caregivers evaluated using the Caregiver Burnout Scale and Involvement & Evaluation questionnaire to understand the caregiver burnout and involvement in care management of Amyotrophic Lateral Sclerosis.* The obtained data will be analyzed using descriptive and inferential statistics.

Results: Caregivers struggled to understand the nature of the illness and uncertainty of diagnosis and faced significant challenges in caregiving. Detailed results will be presented.

Conclusion: There is a need to develop the components caregiving stress so as to address them to prevent burnout as the disease progresses.

Keywords: Caregiver, burnout, Involvement, ALS, Care management.

OP-161_161

Unmet Needs During End of Life in Dementia: Caregiver's Perspectives

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Background: There are about 5.3 million people living with dementia in India. People living with dementia may live in the advanced stage for several years, or even die before they reach the advanced stage of dementia. The needs are very complex and diverse; many are considered unmet needs, especially during the end of life. Informal care provided by the family members are the mainstay for dementia, and with the uncertain trajectory of dementia, caregivers often struggle to navigate the advanced stages well. The present study aimed to understand the caregiver's perception of the unmet needs in Dementia during the end of life.

Methods: The present study adopted a qualitative approach. Five bereaved primary caregivers (3 males and 2 females) of people who were living with dementia and were receiving treatment in a tertiary referral care centres in South India were recruited purposively. The caregivers were interviewed with the help of a semi-structured interview through telephone. End-of-life care is defined as care provided in the last 1 month of life. The recorded interviews were transcribed and thematically analysed using Braun & Clarke method.

Results: The identified themes are '*Structure and process of care*' which include the need for specialized care services and the need for home care services, '*Psychological aspects of care*' which include emotional support (isolation, depression, anxiety, restlessness, behavioural issues, aggression, confusion, and violent behaviour) as well as management of cognitive changes (cognitive issues, forgetting daily affairs, and inability to maintain a relationship with families and other people, '*Physical aspects of care*' which include the care for progressive physical symptoms (inability to do the daily activities, communication difficulty, pain, urinary incontinence, weakness, respiratory problems, dysphagia, indifference to food, nausea, and vomiting) and need for controlling the secondary complications of treatment, '*Need for comfort care*' which includes improving the quality of life through relieving pain and other painful factors and providing practical, emotional, and spiritual support contextualised to patients' culture, '*Social aspects of care*' which include the need for empowerment of caregivers (the necessity of informational, mental, and emotional support for caregivers), '*Cultural aspects of care*' which include the need for de-stigmatization (stigma causes families to suffer from emotional experiences, such as disrespect, indifference, and discrimination).

Conclusion: Identifying the unmet needs of dementia patients during the end of life can pave the way for the multidisciplinary healthcare team to provide effective solutions to meet the needs and empower caregivers to provide comprehensive care for patients. While end-of-life care is gaining momentum, greater efforts are required to recognize dementia in the terminal stages, and to initiate the dialogue on end-of-life care at an early stage of the illness, allowing the individual to take the lead on determining their own wishes and preferences of care by involving the multidisciplinary health care team.

Keywords: Dementia, End of life care, needs, caregiver

OP-167_149

A Study On Adjuvant Homeopathic Therapy To Enhance Quality Of Life In Cancer as palliative Care

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Background: Cancer is the second leading cause of death and patients seek alternative anti cancer supportive therapies for relief of symptoms. Among CAM therapies homeopathy has turned valuable modality in palliative care.

Objective: Palliative care with adjuvant homeopathic therapy aims at improving quality of life in cancer patients.

Design and methodology: Data from the district cancer hospital (both IPD and OPD) was obtained and analyzed using a randomized sampling method. Study design was formulated in 2 groups. Group 1: standalone conventional anticancer therapy. Group 2: Adjuvant homeopathic therapy. Statistical data analyzed using IBM SPSS 25.0 Version software. ^{Chi2} test applied for quantitative data analysis . Depending on 80% Prevalence of cancer therapy adverse effects, 95% Confidence interval and 10% Permissible error, sample size worked out to be of 30 cases. Prospective subgroup analyses with regard to quality of life and survival time was performed in 4 domains of life.

Results: Quality of life as functional and on symptom scale showed significant improvement in the 2nd group than with 1st group ($P< 0,001$) median survival time was significantly longer in the group. (435 days) versus 1st group (257 days) $P = .010$.

Conclusion: In this study homeopathic medicines were well tolerated . However with small sample size and only limited data on improving quality of life, findings are inconclusive. So,research with a larger sample size is recommended.

Keywords: Cancer, palliative care, complementary medicine. djuvant Homeopathy.

OP-168_150

Comparison Between Pulsed Radiofrequency Ablation And Continuous Radiofrequency Ablation of Splanchnic Plexus for Pain Relief and Mortality Benefits in Patients with Upper Abdominal Cancers

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Aims and Objectives: The study compares the efficacy of Pulsed RFA and Continuous RFA in relieving Pain, in improving Quality of Life, in reducing Daily Morphine Dosage and also compares their mortality benefits amongst patients suffering from upper abdominal cancer.

Methods: 56 patients presenting to KGMU Pain OPD with intractable pain (VAS>=4) due to upper abdominal cancers despite taking oral morphine were randomly divided into two groups of 28 each. In this Double Blinded, Randomized Controlled study, splanchnic plexus block was given using PRF at 42^0C for 7 mins to group 1 and CRF at 80^0C for 90 seconds to group 2 using fluoroscopic guided technique. They were followed at 15 days, 1 month, 3 months, 6 months for assessing their pain using Visual Analogue Scale, quality of life using Edmonton Scale and Daily Oral Morphine dose. Mortality benefits were also compared at the end of 6 months.

Results: Mean reduction in VAS Score was more for group 2 than group 1 at all follow ups and the difference was statistically significant at 1, 3 and 6 months. Mean Edmonton score and Daily morphine dosage significantly reduced in both groups at 15 days but at subsequent follow ups these variables increased in both groups, the increase in group1 being more than group 2.The mean survival time was slightly more in group 2 even though the difference was insignificant between both the groups.

Conclusion: Continuous RFA provides better and prolonged pain relief when compared to Pulsed RFAbut no significant difference between both the methods is seen when comparingthelong term improvementsinthe quality of life, opioid consumption and mean survival time.

OP-175_155

Knowledge and attitudes of Indian and other south asian youth in the US towards Palliative and Hospice Care

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Introduction: South asians including people of indian origin are one of the fastest growing populations in the us. Little is known about their knowledge of, and attitudes towards palliative care.

Aim: This study explored US South Asian youths' knowledge of, and attitudes towards, palliative and hospice care.

Methods: Thirty six undergraduate students of South Asian heritage (including 26 of Indian origin) participated in ten focus group discussions. Data were coded thematically by four trained persons working in pairs. Disagreements were resolved through discussion.

Results: Participants were in consensus that if patients had an incurable, fatal condition, keeping them comfortable was important. Several participants were unaware of the terms 'hospice' and 'palliative care'. After these terms were explained, some opposed hospice care. Reasons given were that it was a 'foreign' concept, being around 'strangers' was not comfortable and that living in an environment where others are also sick was undesirable. Some were opposed to even home hospice fearing that it would continuously remind the family and patient about impending death and demoralize them. Several participants preferred taking care of the patient themselves, not realizing that special skills may be required. One participant emphasized the importance of values and said she would support hospice use if it aligned with the patient's values.

Conclusions: Research is needed on culturally-appropriate modes of palliative care education and advocacy for Indian and other growing South Asian populations in the US, especially youth, that are often the decision makers for the care of elderly family members.

OP-176_153

Palliative Care Consultation Service at a Tertiary Care Centre in India- A Brief Report of Impact of Integration with Other Specialities

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Introduction: A palliative care consultation service (PCCS) helps the primary treating physician by providing medical recommendations which are crucial in patient care. An established palliative care department requires a PCCS in addition to out patients and inpatient wards.

Aim: Our aim was to evaluate the need and reach of PCCS to various departments in our hospital.

Methods: This is a retrospective single center observational study, which is being conducted at B.R.A. IRCH New Delhi for a period of one year from November 2021 till October 2022. We included inpatient consultations received in palliative medicine department from various specialty departments of AIIMS, New Delhi over this time period. Patient characteristics and symptom burden were assessed from the medical records.

Results: PCCS received calls varying between 60 to 137 per month with an average of 75. A total of 903 patients were referred to PCCS by various departments which includes 427 males and 476 females with their mean age being 57.4± 2.3. Majority of calls were received from medical oncology (37.8%) and Radiation oncology (31.1%). Among non-oncological departments, maximum number of calls were received from General medicine (42), Pulmonary medicine (38), Geriatrics (27) and Neurology (22). Minimum number of calls were from surgical department. The most common indication for referral were Pain (76.2%), prognostication (32.4%) and end of life care initiation (18.6%). Less common indications included dyspnea, nausea and vomiting, constipation, fatigue, malignant wound, anxiety and depression.

Conclusion: PCCS highlights the importance of integration of palliative medicine with other specialties for improving the quality of patient care. Similar model of care should be started at all levels of public health care delivery system.

OP-181_158

Need for Paediatric palliative care services for Chronic Neurological conditions: Case Study

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Background: About 21 million children aged up to 19 years need palliative care every year and about 2.5 million children die every year due to serious health condition. About 66% of the countries do not have paediatric palliative care Access to palliative care for children is an "ethical responsibility of health systems. Paediatric neurological conditions such as mitochondrial disease, sub-acute sclerosing pan encephalitis, Duchene muscular dystrophy, Spinal muscular atrophy, Static encephalopathy, spastic quadriplegia, spina bifida need immense palliative and end of life care support. WHO defines palliative care for children as the "active total care of the child's body, mind and spirit, and giving support to the family. It starts when a diagnosis is made and continues regardless of whether the child receives treatment or not. Palliative care for children requires a broad multidisciplinary approach that includes the family and makes use of available community resources.

Aim: To integrate paediatric palliative and end of life care services for chronic neurological disorders in a tertiary care hospital setting.

Methodology: Case study approach was used and three case studies (15 years old female child with SSPE, 6 years old male child with DMD, stroke in 18 years old female) would be discussed in detail to provide deeper understanding on palliative care services by multi-disciplinary team on addressing psychosocial needs for both caregivers and children with chronic and life-limiting neurological conditions. CARE guideline was followed for reporting.

Conclusion: Paediatric Palliative care services for children with neurological conditions are still its infant stage in India. It is feasible to provide comprehensive paediatric palliative care for chronic neurological disorders in a tertiary care hospital setting. Psychiatric social workers play a vital role in neuro-palliative care for this population. Grief counselling, bereavement therapy, and support group of parents who lost their children. The hospital services and crisis intervention should be continued even after the decease of the child as the family go through a difficult phase.

Keywords: palliative medicine, neurological disorders, psychiatric social work interventions

OP-204_193

End of life care in MND in India - a qualitative inquiry into the needs and experiences from a caregivers perspective

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Introduction: Motor Neuron Disease (MND) is a relentlessly progressive neurodegenerative condition with complex needs throughout the course of illness. MND is one of the non-cancerous conditions where the palliative care approach in the management of the disease is practiced even from the early years of palliative care. With the emergence of subspecialties in palliative medicine in India, there is an implication to understand the needs of MND patients in India, especially the needs at the end stages where the expertise of palliative care professionals is sought.

Aim: To understand the needs and experiences of people with MND in the last month of life, from the perspective of family caregivers

Method: In-depth interviews were conducted using a semi-structured interview schedule among 6 family caregivers of the decedent MND patients who have consulted at a quaternary care center for neurological conditions in South India, and who succumbed to illness within the last 18 months. The interviews were recorded, transcribed and data analyzed using Braun and Clarke's stepwise thematic analysis.

Results: The age range of participants was 20-66 years, with an average of 14.3 years of education. The patients were predominantly males (5:1). Out of the 6 patients, 5 had limb onset and 1 had bulbar onset MND. All 6 of them had respiratory symptoms in the last few weeks to months of life. 5 out of 6 patients had marked breathlessness and decline in functional status in the terminal phase. The event that led to death was choking in 1 patient who had bulbar onset MND. None of them were on alternative feeding methods. 1 out of 6 patients used Non-invasive ventilation in the last 1 month. The major themes that emerged from the analysis were the need for information about disease progression, absence of awareness of supportive care among caregivers, physical burden on caregivers, feeling of helplessness, and need for increased awareness among healthcare professionals (HCPs) about the management of MND. Emergency hospital visit in the terminal phase was common to all the patients, indicating the need for appropriately recognizing and guiding them for the end of life.

Conclusion: Preparation for End of life in MND should be initiated from early in the course of the disease which gives an opportunity for meaningful conversations among the patients, family caregivers, and HCPs. Adequate knowledge about the illness empowers the patients and family caregivers in making informed decisions and coping with the disease progression. Given the heterogeneous nature of the trajectory of illness, it's important to regularly evaluate the patient's condition for early interventions and to provide adequate supportive care to navigate through the illness. Given the complex needs and rarity of the condition, there is a need to explore and establish ways to improve awareness among HCPs and coordinate the care of the patients which will reduce the suffering of people with MND.

OP-205_177

Social Challenges faced by children with Duchenne Muscular Dystrophy-A Qualitative Study

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Introduction: Duchenne muscular dystrophy (DMD) is characterized by muscle damage and progressive loss of muscle function in male children. DMD is one of the most devastating genetically linked neuromuscular diseases for which there is currently no cure. Children suffering from this disease eventually become non-ambulant and succumb to the illness in their late teens. Social interactions and the development of social relationships, that is crucial as the child transitions to adolescence, have the potential to be particularly problematic for children with DMD. Therefore, the present study was conducted to investigate the challenges faced by the children with Duchenne Muscular Dystrophy in the social sphere.

Methods: The present study adopted a qualitative approach. Six children between the age of 14 to 17 with the diagnosis of Duchenne Muscular

Dystrophy who were receiving treatment in neuromuscular disorder clinic in a tertiary referral care centers in South India were recruited purposively. The children were interviewed with the help of a face-to-face semi-structured interview as well as through telephone. The recorded interviews were transcribed and thematically analyzed using Braun & Clarke method.

Results: The major identified themes are *social stigma* which is associated with symptoms and disease condition, *school related problems* which include difficulty in learning, difficulty in travelling to school, peer group related issues, non-supportive teachers and mentors, difficulty in staying in the classroom for long period of time, difficulty in using lavatory at school, *lack of social support* from non-family and community, *financial issues* (purchase of medicines, regular follow-up) and *lack of involvement in recreational and social activities* (play, family functions).

Conclusion: The study highlighted that the children with DMD face a complex social problem which is identified by themselves as well as the caregivers. Parents may then be better positioned to support their child in looking forward. Greater efforts are required to improve the quality of life of the patient by improving the social support through sensitizing the teachers and peers about the trajectory of the disease and the need for empowering these children to improve the social skills. Active physiotherapy, genetic counselling and other supportive therapies would also help them to improve the wellbeing. Our ongoing work using additional robust scales of social communication will more thoroughly characterize the behavioral profile associated with DMD.

Keywords: Duchenne muscular dystrophy, social challenges, children.

OP-206_195

Can Frailty Assessment at Dialysis Initiation Predict Outcome?

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Frailty is a multidimensional construct reflecting the decline in health and functioning observed in the elderly, ultimately resulting in increased risk for disability, hospitalization, institutionalization, and death. Epidemiological surveys have shown high prevalence (5- 20%) from various parts of the world including India. The construct of frailty has been associated with adverse outcomes among elderly individuals, but the prevalence and significance of frailty among patients with end-stage renal disease in india have not been established. The aim of the current study was to determine the prevalence and predictors of frailty among a cohort of dialysis patients and to determine the degree to which frailty was associated with death and hospitalization. Given its prevalence and consequences, increased research efforts should focus on interventions aimed to prevent or attenuate frailty in the dialysis population.

Aim: The purpose of this study was to assess if there was an association between the degree of frailty at dialysis entry and the outcome - mortality among patients on incident dialysis.

Methods: 1. Retrospective analysis of dialysis case records of CKD in KMC during the period 2020-2022. 2. On the basis of overall clinical impression, the Clinical Frailty Scale (CFS) score was determined for patients at the start of dialysis by 2 observers and getting the mean value. The Canadian Society of Health and Aging CFS was used. 3. This simple scale allocates a single point to different states of frailty (1, very fit; 2, well; 3, managing well; 4, vulnerable; 5, mildly frail; 6, moderately frail; 7, severely frail 8, very severely frail 9, terminally ill). 4. Primary outcome – Death, hospitalisation. 5. Patient survival data - Kaplan Meyer curve. 3. Following data recorded.

a. Complications during dialysis
b. Number of hospitalisations
c. Medical expenses
d. Baseline characteristics

Inclusion criteria: 1. Consecutive patients entering dialysis program with the diagnosis of CKD 5. 2. Age > 18 yrs.

Exclusion criteria: 1. Acute on CKD. 2. Underlying malignancy. 3. Those who died within 4 weeks. 4. Those lost to follow up or transferred to other centers within 4 weeks.

Results: The data collection and statistics are being analyzed and hence will be presented at the time of conference.

OP-209_197

Effectiveness of Awareness Talk for Cancer Patients' Family Care Givers on Mitigating Cancer Myths

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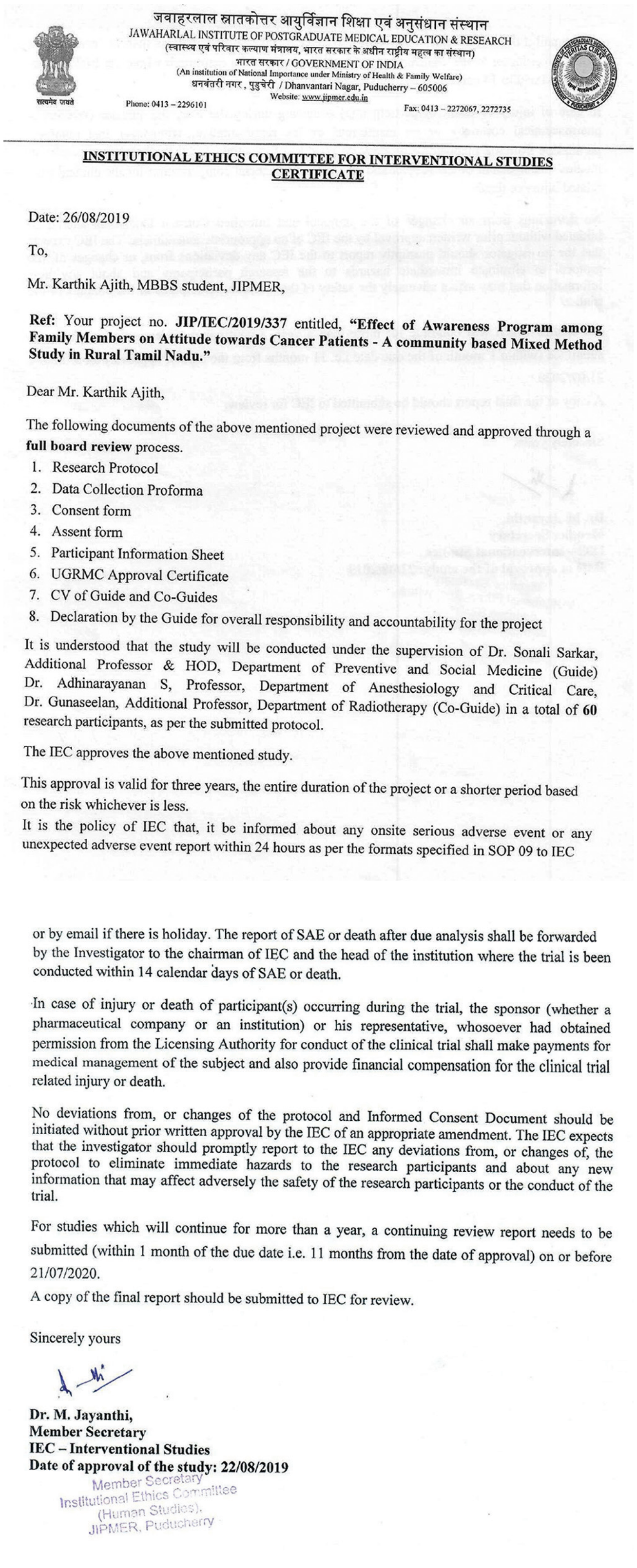
JIPMER,Puducherry (affiliation where the work is carried out)

Introduction: Home-based palliative care is crucial to holistic oncologic palliative care. Myths about cancer among family caregivers can seriously affect the quality of life and treatment outcomes. Awareness programs for myths related to cancer may help to improve the care for cancer patients.

Aim- The study aimed to evaluate the effectiveness of cancer awareness program on mitigating myths related to cancer and improving attitude towards cancer patients among family caregivers.



जवाहरलाल स्नातकोत्तर आयुर्विज्ञान शिक्षा एवं अनुसंधान संस्थान
JAWAHARLAL INSTITUTE OF POSTGRADUATE MEDICAL EDUCATION & RESEARCH
(स्वास्थ्य एवं परिवार कल्याण मंत्रालय, भारत सरकार के अधीन राष्ट्रीय महत्व का संस्थान)
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INSTITUTIONAL ETHICS COMMITTEE FOR INTERVENTIONAL STUDIES CERTIFICATE

Date: 26/08/2019

To,

Mr. Karthik Ajith, MBBS student, JIPMER,

Ref: Your project no. **JIP/IEC/2019/337** entitled, **"Effect of Awareness Program among Family Members on Attitude towards Cancer Patients - A community based Mixed Method Study in Rural Tamil Nadu."**

Dear Mr. Karthik Ajith,

The following documents of the above mentioned project were reviewed and approved through a **full board review** process.

1. Research Protocol
2. Data Collection Proforma
3. Consent form
4. Assent form
5. Participant Information Sheet
6. UGRMC Approval Certificate
7. CV of Guide and Co-Guides
8. Declaration by the Guide for overall responsibility and accountability for the project

It is understood that the study will be conducted under the supervision of Dr. Sonali Sarkar, Additional Professor & HOD, Department of Preventive and Social Medicine (Guide) Dr. Adhinarayanan S, Professor, Department of Anesthesiology and Critical Care, Dr. Gunaseelan, Additional Professor, Department of Radiotherapy (Co-Guide) in a total of **60** research participants, as per the submitted protocol.

The IEC approves the above mentioned study.

This approval is valid for three years, the entire duration of the project or a shorter period based on the risk whichever is less.

It is the policy of IEC that, it be informed about any onsite serious adverse event or any unexpected adverse event report within 24 hours as per the formats specified in SOP 09 to IEC or by email if there is holiday. The report of SAE or death after due analysis shall be forwarded by the Investigator to the chairman of IEC and the head of the institution where the trial is been conducted within 14 calendar days of SAE or death.

In case of injury or death of participant(s) occurring during the trial, the sponsor (whether a pharmaceutical company or an institution) or his representative, whosoever had obtained permission from the Licensing Authority for conduct of the clinical trial shall make payments for medical management of the subject and also provide financial compensation for the clinical trial related injury or death.

No deviations from, or changes of the protocol and Informed Consent Document should be initiated without prior written approval by the IEC of an appropriate amendment. The IEC expects that the investigator should promptly report to the IEC any deviations from, or changes of, the protocol to eliminate immediate hazards to the research participants and about any new information that may affect adversely the safety of the research participants or the conduct of the trial.

For studies which will continue for more than a year, a continuing review report needs to be submitted (within 1 month of the due date i.e. 11 months from the date of approval) on or before 21/07/2020.

A copy of the final report should be submitted to IEC for review.

Sincerely yours

Dr. M. Jayanthi,
Member Secretary
IEC – Interventional Studies
Date of approval of the study: 22/08/2019

Member Secretary
Institutional Ethics Committee
(Human Studies),
JIPMER, Puducherry

Methods: This was a mixed methods study done in August 2019 among family caregivers of cancer patients in two districts of Tamil Nadu, with explorative design in the qualitative part and pre, post intervention as quantitative part of the study. Six in depth interviews were conducted among family caregivers for developing the interview schedule and content of the awareness program. Myths and attitudes towards cancer patients were assessed for all 50 members recruited, before and two weeks after delivering the structured individualized awareness program.

Results: A structured interview schedule was prepared based on 14 identified myths related to cancer from the in-depth interviews. Total favorable responses rose from 61.28% pre intervention to 77.28% post intervention. The awareness program corrected widespread myths, "surgery increases spread of cancer" and "cancer is contagious" with 64% and 36% increases in favorable responses for these questions, respectively.

Conclusion: Major proportion of myths related to cancer were corrected by a cancer awareness program which can be given to the family members of cancer patients at the time of diagnosis.

Main Category – Track 3: Oncology Palliative Medicine.
Sub Category: Family Caregivers.

A part of the study's results were presented in other conferences and is accepted for publication in the Journal of Family Medicine and Primary Care. All of these were under the title "Myths, Beliefs and Attitude towards Cancer among the family care givers of cancer patients: A Community based Mixed Method Study in Rural Tamil Nadu."

Evidence of ethics approval.

OP-210_181

Identifying Referral Patterns of Patients from Neonatal Intensive care unit to Palliative Medicine in a Tertiary University Teaching Hospital – Retrospective audit.

Dr Gayatri S[1], Dr Krithika S. Rao[2], Dr Aswathi Praveen[1], Dr Anuja Damani[2], Dr Naveen Salins[3], Dr Lesley Lewis[4], Dr Sheela Mathias[5]

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Introduction: Neonatal mortality rate in India as reported in 2020 is 20 per 1000 live births as against 15 in developed world. The major causes of neonatal deaths are prematurity& low birth weight (46.1%), Birth asphyxia and birth trauma(13.5%), Neonatal Pneumonia(11.3%), sepsis (5.7%), congenital anomalies(4.3%). According to Catlin and Carter, palliative care for neonates is "an entire milieu of care to prevent and relieve infant suffering and improve the conditions of living and dying". There is negligible penetration of palliative care in the neonatal intensive care setting in India.

Aim: 1. To identify patterns of referral from NICU to palliative medicine. 2. To assess the length of palliative care input during hospital stay.

Methods: Data was extracted from medical records from January 2019 to December 2022 with hospital approval and Descriptive statistics used for analysis.

Results: There were 25 neonates referred during the study period, 52% of whom were inborn. Of the 52% preterm infants, 23% were extremely preterm, 15.3% were very preterm and 61.5% were late preterm. The most common diagnoses at the time of referral amongst preterm neonates is severe respiratory distress syndrome. Of the 48% of the term neonates, 41.6% with perinatal asphyxia and HIE, 33.3% neonates with structural musculoskeletal defects and 8.3% each of functional metabolic defect and neural tube defects were referred to palliative medicine for exploring goals of care with the parents and providing support. The mean average duration of palliative medicine input is 2.48 days with interquartile range between 1- 30days during the hospital stay.

Conclusion: Neonatal palliative care services accessed earlier help relieve babies suffering due to distressing symptoms and offer parents much-needed emotional and decision-making support, and liaison with other healthcare workers in the hospital.

OP-216_186

Expanding Access to Children's Palliative Care Education for Humanitarian Settings through an E-Learning Course

Doherty, M[1,2,3], Das, E[1], & Daniels A[4]

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Introduction: Palliative care is recognized as an essential component of humanitarian emergency responses, but its provision has largely been neglected. Limited knowledge of palliative care and how to manage pain and other symptoms in children are significant barriers to improving palliative care availability in humanitarian settings.

Aim: To develop and implement an e-learning program, adapted to the specific situations and challenges of delivering children's palliative care (CPC) in humanitarian settings.

Methods: In partnership with PallCHASE (Palliative Care in Humanitarian Aid Situations and Emergencies) and ICPCN (International Children's Palliative Care Network), experienced CPC clinicians, including those with experience in humanitarian settings, developed learning content after reviewing relevant literature and existing online learning materials.

Results: The course has 4 modules: (1) What is CPC, (2) End of Life Care, (3) Pain and Symptom Care, (4) Communication and Psychosocial Family Care. The following learning outcomes were developed: participants will be able to (1) Define CPC and identify when it should start; (2) Describe why CPC is needed and by which children; (3) Describe how to provide key elements of CPC. Since the course launched 6 months ago, 67 participants from 26 countries have enrolled, including counsellors (30%), doctors (24%) and nurses (21%). A WhatsApp group was created for learners interested to interact while completing the course, and 2 online Zoom-based discussions were arranged for these learners.

Conclusions: The use of e-learning courses can expand access to CPC education for health care workers in humanitarian settings and the use of social media to develop peer-to-peer knowledge sharing may further enhance learning.

OP-219_188

Healthcare professional's perspectives of the life of Children and Adolescents living with Duchenne Muscular Dystrophy (CALD)

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Introduction: Children and adolescents living with DMD (CALD) face several psychosocial problems, and it is important to understand and address those in every stage of the illness. As the hospital visits and health care providers are integral in the life of CALD, their perspectives on CALD's emotions, treatment and participation, needs, rights and overall impact of the illness becomes important.

Aim: To explore the healthcare professionals' perspectives on the life of the CALD

Method: Seven healthcare professionals with expertise in working with children with DMD were interviewed in- depth. The participants were routinely involved in service provision at a national care centre for neurological illnesses. The interviews were conducted with the help of a semi-structured topic schedule, and were audio recorded. Those interviews were transcribed and subjected to thematic analysis.

Result: The participants included neurologists, psychiatrist, psychiatric social workers, and physiotherapists. The major themes derived from the analysis are as follows- *Scarcity of time-* inability to spend adequate time in general healthcare settings. *Specialized communication* emphasising systematic and friendly communication by trained professionals. *A sensitive approach* to explain the illness, transitions, understanding their needs, crisis management, and mental health problems. *Disable Friendly hospitals* with easy access to amenities. *Continuous support services* like physiotherapy, assistive devices, support groups, commutation and palliative care services to maintain quality of life.

Conclusion: The understanding of the perspectives of the health care providers could help to develop standard operating procedures and guidelines for the health care settings and providers to ensure appropriate care for CALD.

OP-220_248

Palliative Care in Intensive Care Unit (ICU)

Dr.Rabiya Abdu Razak Malayil,Dr Sushma Bhatnagar

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Introduction: Palliative care aims to improve and maintain the quality of life of all patients and their families at any stage of life threatening illness, therefore all critically ill patients should be provided palliative care until the end of their lives.The combined model of palliative care is the key to ensure the quality of standard palliative care and continuity of care even when the patients are discharged from ICU.

Aim: This inpatient audit was performed to assess the integration of palliative care in ICU to set patient centered goals of care,to alleviate physical symptoms and to provide end of life care.

Methods: After obtaining permission from the Institute's ethical committee,data were retrospectively collected from the medical records of patients admitted to the ICU between December 2021–November 2022.

Results: Inclusion criteria were fulfilled in 122 patients, consisting of 49 females and 73 male, mean age was 45.8 years (31-52 years).Majority of the patients n=62 was shifted from palliative care ward, 23 patients underwent palliative surgery and was shifted to ICU for post operative care, 37 patients were shifted directly from Emergency department. Diagnosis at the time of ICU admission were head and neck cancer 13%, esophageal cancer 8%, lung cancer 19%, breast cancer 8%, gastric cancer 4% and miscellaneous cancers 54%. Palliative surgeries like feeding jejunostomy/gastrojejunostomy-4 patients,exploratory laprotomy 3 patients and diversion colostomy 2 patients respectively. Symptomatic management was done - analgesic titration 53%, management of dyspnea 26% and terminal sedation 25%. Clinical decision making during palliative care in ICU -73% patient's relatives after counseling and prognostication had signed DNR/DNI and End of life care was initiated,12% patients were transferred out to palliative care ward and 37% patients were discharged for Home based care.

Conclusions: Integration of palliative care in the ICU improves the quality of life in critically ill patients, shortens hospital stay and reduces the use of emergency resources.

OP-235_210

Nephrologist's perspective on comprehensive conservative care in end stage renal disease: A survey from India

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Introduction & Aim: The renal supportive care is still in infantile stage in our country and there is a need for the same to reduce overall health-related suffering of our ESRD patients on dialysis and to improve their quality of life. The present survey attempted to understand nephrologist's perceptions and experience in utilizing Comprehensive Conservative Care in situations involving elderly Dialysis patients or Dialysis patients with significant comorbidities.

Methods: We used an online google based survey form among practicing nephrologists in India. The survey comprised of 13 questions and answer choices which reflected the perceptions, experience, barriers and their opinion on how to implement and improve use of comprehensive conservative care in end stage renal disease patients undergoing dialysis.

Results: Total of 55 nephrologists completed the survey having experience ranging from less than 5 years to more than 20 years. The group represented all type of practitioners and majority were males. Most of the nephrologists (76%) were not regularly using validated screening tools to assess/monitor physical/psycho social needs of dialysis patients during their regular rounds/ clinic and only 44% of them used to apply the "Surprise Question" as a prognostic tool during dialysis rounds to decide on patient's goal of care. Almost all (97%) agree and say that they discuss the option of conservative kidney care especially in >75years old ESRD patients (Always: 33%, Often: 42% Sometimes: 22%, Never: 3%) and majority (93%) felt that patient's family is as important as patient in decision making of conservative care especially in our country. But among dialysis patients who are not doing well routinely, only 57% of nephrologists said that they discuss end of life care / withdrawal of dialysis in their practice. 78% of participants felt it was not morally distressing to discuss conservative care and nephrologist definitely has a role in offering conservative kidney care (75%). But only 16% were very comfortable in discussing end of life decisions with their patients. The common hurdles that prevent them discussing conservative care were legal (18%) and time constraint (13%). Almost all (97%) participants emphasize that there is need to improve capability of Indian nephrologists in offering conservative care by various means of education (CME, Training & Certified courses). 75% of the participants felt that integrating palliative care will help in improving quality of Comprehensive Conservative Care.

Conclusions: There is a lack of use of clinical tools among nephrologists during their day-to-day practice and only few are very comfortable in discussing end of life care and withdrawal of dialysis. Majority are keen to implement comprehensive conservative care and agree that it can be provided effectively to ESRD patients with involvement of the palliative care team and there is a need for further training for nephrologists.

OP-236_208

Development and Implementation of Kerala State Palliative Care Policy 2008 & 2019 : Swot Analysis

Oral Presentation

Category: Policy or Programme Advocacy, Development and Evaluation

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Introduction: Kerala was the first state in India and first government in the developing world to adopt a palliative care (PC) policy. Currently the primary health system has one nurse with training in PC providing home visits to non-ambulant patients. The state has revised policy in 2019 aimed for integration of PC into all disciplines of medicine, enhancing capability of health system and service providers.

Objectives: To explore the strengths and weakness of PC policies of 2008 and 2019.

Methods: The study employed multiple approach including qualtitative and qualitative methods. The data was collected using chronological media review, key informant interviews with policy makers, in-depth interviews with health care providers and beneficiaries and cross sectional survey to cappture beneficarie's satisfaction. The analysis was done based on "SWOT analysis" framework.

Results: The new policy calls for integrating PC into all medical specialties, improving capacity of healthcare system and service providers to meet state's PC needs, forming partnerships with all stakeholders, private health sector, and Ayush services. However, as evidenced by per capita opioid consumption, inadequate involvement of doctors in PC, lack of access to PC in tertiary hospitals, poor implementation of proposed monitoring machinery, inequity in care, poor collaboration between the government and non-governmental organisations are he key areas require strengthening.

Conclusions: The state policy represents a significant improvement in access to treatment and a wise choice to end millions of people's suffering, but it still requires a monitoring mechanism and corrective action to close existing gaps.

OP-251_268

Integration of Palliative Care into Hospitalized Care of Chronic Diseases - Enablers and Disablers: A Qualitative Study

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Background: Hospital stay provides an excellent opportunity for Introduction of Palliative care for overall management of patients with chronic diseases. However, this has been variable and generally not adequate.

Aim: To understand barriers and facilitators of introduction of palliative care for patients hospitalised with chronic conditions.

Methods: Semi-structured interviews were conducted with Anaesthesiologists, Internists, Intensivists, and palliative care physicians to understand their experiences in providing care to patients with chronic conditions. Results are analysed using thematic analysis.

Results: Twenty healthcare providers who work in ICUs (five each of anaesthesiologists, palliative care specialists, intensivists, and hospital administrators) in urban areas are interviewed. Six thematic categories are included - patient factors, provider factors, Disease-related factors, palliative care knowledge, palliative care service factors, and administration factors. Patient factors include demography, socio-economic factors and goals of care. Provider factors include available time, attitude, and practices. Disease-related factors include illness trajectories, treatments, and outcomes. Palliative care knowledge include perceptions about eligibility for palliative care, palliative care skills, and decision-making for quality of life in chronic condition management. Palliative care service factors are accessibility and adaptability. Administration factors included hospital-mandated support, leadership and infrastructure.

Conclusion: Results are being analysed and will be presented at the conference. Study findings would provide insights for planning interventions to promote integration of palliative care as part of comprehensive management of chronic diseases.

Keywords: Palliative care, facilitators, barriers, end of life, access to care, specialist palliative care, primary palliative care.