1ST NATIONAL CONFERENCE FOR CHILDREN’S PALLIATIVE CARE MALAYSIA
6th - 8th October 2022

ABSTRACTS

Swiss Garden Hotel, Kuala Lumpur, Malaysia

Theme:
Supporting from the beginning

Co-organized by:
Malaysian Association of Paediatric Palliative Care and
Ministry of Health Malaysia
SUPPLEMENTARY
1ST NATIONAL CONFERENCE FOR CHILDREN’S PALLIATIVE CARE MALAYSIA, 6-8 OCTOBER 2022

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Abstract

**Objective:** To improve the quality-of-care for seriously ill children (SIC), care providers would benefit from measuring and reporting care processes valued by the families of SIC. We aim to develop a comprehensive parent-reported experience measure (PaREM) consisting of key process indicators of quality-of-care for SIC. **Methods:** Stage 1: scoping review of existing PaREMs, including identifying gaps of current measures (completed). Stage 2: inductive grounded theory study exploring care processes prioritized by parents of SIC (completed). Stage 3: Delphi expert panel review of key informants to attain consensus on candidate indicators (completed). Stage 4: Pre-testing to ensure comprehension and acceptability (on-going). Stage 5: Pilot-testing to refine the survey protocol and ensure data completeness (forthcoming). Stage 6: Validation of the PaREM amongst parents of SIC to assess its measurement properties (forthcoming). **Results:** Stage 1 revealed a lack of PaREMs applicable to SIC that can be used across care settings (both health and social). Stage 2 culminated with a theoretical framework termed “PaRental perspectives on high quality care for Children with sErious iLlnESSes (PRICELESS)” consisting of seven components encompassing high-quality care and generated 64 quality-of-care process indicators. In Stage 3, we obtained consensus on 75 process indicators and drafted a novel PaREM, termed PaRental Experience with care for Children with serIOUS illnesses (PRECIous). We now plan to validate the instrument in Singapore and Malaysia. **Conclusion:** Once validated, PRECIous will enable standardized evaluation of quality initiatives and inform the development of targeted multicomponent interventions, ultimately improving the quality-of-care for SIC and families.

**Keywords:** Quality of Healthcare, Process Assessment, Health Care Surveys
THE IMPACT OF MEANING MAKING INTERVENTION ON FAMILY OF PAEDIATRIC PALLIATIVE PATIENTS

Noor Suraya Muhamad*, Anila Perumal

1Psychology Counselling Unit, Hospital Tuanku Ja’afar, Jalan Rasah, Bukit Rasah, 70300 Seremban, Negeri Sembilan, Malaysia
2Medical Department, Hospital Tuanku Ja’afar, Jalan Rasah, Bukit Rasah, 70300 Seremban, Negeri Sembilan, Malaysia

*Corresponding Author: Noor Suraya Muhamad (nsuraya.muhamed@moh.gov.my)

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Abstract

Palliative care is a holistic approach for patients with life limiting illnesses and aims to alleviate suffering using a BioPsychoSocial Spiritual approach. According to Victor Frankl (1986), he concluded that the will to meaning and self-transcendence are essential for survival and healing. Suffering without meaning will lead to despair and depression. Meaning makes suffering more bearable. Objective: To examine the influences of meaning making to determine its impact on a patients’ family sense of healing, extend understanding of meaning making and its activities for family of paediatric palliative patients diagnosed with a chronic or life limiting illness and explore the association on how meaning making may lead to an outcome of psycho-spiritual healing or impair distress. Methods: A total 10 participants were approached based on convenience sampling with 8 participants enrolled. Interviews were conducted in the Paediatric Ward including Paediatric Intensive Care Unit (PICU). Screening for eligibility was based on palliative care clinician referrals. The 3 sessions involved semi-structured interviews oriented toward eliciting the sequence of experiences and decisions that led to selected answers on the HEALS and meaning making activities. Results: The overall theme emerged indicating a strong emphasis on meaning making through the relationship with divine entity, development of meaningful relationships with family, friends and compassion towards others, and the other theme is the less stressor which means develop meaning in the process of psychosocial spiritual healing. Conclusion: Modified approach centred in meaning making activities for families of paediatric palliative patients gave significant impact on healing and self-transcendence.

Keywords: Paediatric Palliative, Meaning-making, Psychotherapeutic
INTRODUCTION OF MUSIC AND ART THERAPIES TO PATIENTS WITH CHRONIC LIFE-LIMITING GENETIC DISORDERS: A PILOT PROJECT IN A DAY-CARE SETTING

Ch’ng Gaik-Siew1*, Andrew Jack Nelson2, Loh Ee Chin3

1Department of Genetics, Penang General Hospital, 10460 Georgetown, Penang, Malaysia
2Department of Genetics, Hospital Kuala Lumpur, 50586 Kuala Lumpur, Malaysia
3Department of Palliative Care, University Malaya Medical Centre, 50603 Kuala Lumpur, Malaysia

*Corresponding Author: Ch’ng Gaik-Siew (gaiksiew@yahoo.com)
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Abstract

Objective: Music and art provide creative opportunities for patients and caregivers to express emotions within an atmosphere of comfort and relaxation. It reduces anxiety and physical effects of stress, improves overall sense of well-being, and reduces depression and psychological symptoms related to chronic, debilitating and life-limiting disorders. Music and art therapies were introduced to complement the medical management of patients. Methods: Patients who attended routine day-care genetic clinic Kuala Lumpur Hospital, for Enzyme replacement therapy (ERT) from July till December 2020 were recruited. Anonymous donors sponsored the sessions conducted by a volunteer music therapist and an art illustrator with training and experience working with special needs individuals. The sessions were conducted concurrently whilst the patients were receiving ERT infusion which lasted an average of 3-4 hours. Total of 17/35 ERT patients were enrolled in either art or/and music therapy, matched with the time schedule of the volunteer therapists. Nine and thirteen patients enlisted for art and music therapy respectively whereas five joined both music and art activity. Results: 11/13 liked music therapy, 6/13 felt positive differences during and after the music sessions; however, 4/13 felt obligated to join. Correspondingly, no one disliked the art activities. A pictogram of expressive arts depicting the beneficial outcomes of the activities will be presented. Conclusion: Majority of participants liked the therapeutic art and music sessions and felt positive differences. These complementary refreshing experiences outside of routine uncomfortable procedures provide a sustainable positive psycho-emotional impact on patients.

Keywords: Music and art therapy, Life-Limiting Genetic Disorders, enzyme replacement therapy (ERT)
Abstract

Objective: Golden Butterflies Children’s Palliative Care Foundation (GB), a four-year old not-for-profit organization based in Chennai, India, works at three levels: direct services to needy child-patients and families, capacity building of healthcare professionals on Paediatric Palliative Care (PPC), and generating awareness on PPC among the public. As a young organization, a large part of this work is handled by trained volunteers and student interns. This study aimed to understand the experiences and motivations of volunteers associated with an organization working on a difficult subject like PPC and note their suggestions for improvement. Methods: In-depth interviews were conducted with 10 volunteers of GB until saturation was attained. Interviews were conducted over Zoom, video-recorded, and transcribed. Data was analysed using a phenomenological approach. Results: Volunteers were mostly middle-aged women, long-time friends of the NGO founder(s), who wished to help with a “noble cause” and volunteered 2 days a month on average. Most had no or only a vague idea about PPC before joining, but unanimously felt a sense of ownership towards GB and the cause. They suggested novel ways of acknowledging and retaining volunteers like curated role progression, ongoing mentoring, skill-enhancement, public felicitation, forming a think-tank for ideation, etc. Conclusion: Volunteering had the positive outcomes of encouraging introverted persons to become friendlier, and outgoing persons to groom themselves further to interact with child-patients, caretakers, and hospital personnel. When aptly motivated, they are willing to go beyond the scope of traditional volunteer roles, to be of service to child-patients and families.

Keywords: Volunteer, experience, paediatric palliative care
Abstract

**Background:** Children with life-limiting or life-threatening diseases, and their families, have diverse and evolving needs: medical, psychological, financial, social, and spiritual- from the time of diagnosis till end of life, at the hospital and in their own homes. **Objective:** To provide continuity in holistic supportive care to child-patients and families as they transition from hospital-based to home-based palliative care through our multi-disciplinary team (MDT). **Methods:** Our Supportive Paediatric (Home) Care service provides a holistic approach to patient care to improve quality of life and leads to reduced cost of hospital care. Our total care includes pain/symptom management, counselling, art/recreational activities, non-formal education, physiotherapy, nutritional support, fulfilling child’s wishes, and bereavement support. Our multi-disciplinary team of 8 members - chief medical officer, nursing officers, social workers/ counsellors, and physiotherapist interacts with child-patients at the hospital and visits them at home after discharge. Our team is a BRIDGE between the hospital and the family. **Results:** Since January 2022, we have touched the lives of 84 child-patients and families with our homecare service through 175+ counselling sessions, 16 art/recreational sessions, 12 medical intervention, and 28 physiotherapy sessions. Doctor referrals to homecare have increased, as they see improvement in Quality of Life (QoL) of child-patients and families. **Conclusions:** Providing continuity of care by consistent service providers at the treating hospital and their own home improves QoL of child-patients and families. A dedicated and committed MDT provides enhanced supportive care and a better acceptance of palliative care for child-patients.

**Keywords:** Quality of life, Paediatric Supportive Care, Continuity of care
Abstract

**Background:** Non-invasive ventilation (NIV) is an alternative ventilatory support which has been found useful in the adult palliative setting. The clinical utility of non-invasive ventilation (NIV) in the paediatric palliative care setting has not been described in the literature. NIV may also be a useful supportive modality in the paediatric palliative care setting. **Objective:** This paper aims to describe the NIV service offered by the Paediatric Palliative and Supportive Care (PPSC) Unit of Hospital Tunku Azizah, Kuala Lumpur. **Methods:** Since 2019, PPSC has offered NIV support for children with life-limiting illnesses who develop acute respiratory distress (ARD). The two main indications are potentially reversible ARD (Category 1) or comfort care at the end of life (Category 2). A standard operating procedure guides the whole process, including selection criteria, NIV provision (initiation, maintenance, weaning and stopping) and patient monitoring (effectiveness and adverse effects). **Results:** Since its introduction, NIV has been offered on 25 different occasions for 22 individual children. Of these, 18 were for Category 1 indication, and 7 were for Category 2 indication. Clinical symptom improvement was recorded in 23 of the 25 occasions. On 18 occasions, NIV was successfully weaned off after recovery from ARD. There were two occasions where NIV was continued post discharge and three occasions where patients passed away while on NIV. Reported adverse events include pressure injury and aerophagia. There were no major complications from NIV use in these patients. **Conclusion:** NIV shows potential benefits in managing ARD in children with palliative care needs.

**Keywords:** Palliative Medicine, Paediatric, Acute respiratory distress syndrome
**CHALLENGES FACED BY CAREGIVERS OF CHILDREN WITH CANCER AT HOSPITAL UNIVERSITI SAINS MALAYSIA, KELANTAN**

**Shamini Subramaniam**, **Fahisham Taib**

Paediatric Department, Hospital Universiti Sains Malaysia, 16150 Kubang Kerian, Kelantan, Malaysia

*Corresponding Author: Shamini Subramaniam (shashacure26@gmail.com)
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**Abstract**

**Objective:** Aim is to identify challenges of caregivers based, physical, psychology, social and spiritual domains. **Methods:** 10 in-patient caregivers of children with cancer who required prolonged periods of hospitalization and treatment were included. The in-depth interview session was audio taped in Malay language. Transcripts were translated to English and thematically analysed. **Results:** Half (n=2) of the father caregivers were unemployed, while all (n=6) mothers were housewives. The domains derived from thematic analysis were physical, psychology, social, spiritual and individual needs. Physical with sub themes includes pain symptoms and changes in body image. There were both positive and negative feelings in the psychology domain. The majority of the caregivers in the B40 group (low socioeconomic group) have echoed financial problems and disrupted family dynamics as part of the sub themes. These features have added to the gravity of challenges for the social domain. In the spiritual domain, the sub themes include finding on the meaning of life and faith. Another extra domain found in our qualitative study was individual needs which represented caregiver knowledge and infrastructure needs. **Conclusion:** Significant findings reflected the understanding of caregiver’s challenges, enabling us to improve a better approach to palliative care in the hospital settings.

**Keywords:** Challenges, caregivers, cancer
**Abstract**

**Background:** Post-infectious bronchiolitis obliterans (PIBO) is an irreversible lung condition where fibrosis and obstruction occur following a lung infection. PIBO sufferers have a shortened lifespan and require prolonged ventilation or long-term oxygen therapy. Unfortunately, many children with PIBO were not referred for paediatric palliative care (PPC). This case report describes the missed opportunities for PPC in a PIBO patient. **Clinical History:** A 23-year-old young man was diagnosed with PIBO at 14 months of age. Following discharge home, he was put on 24-hour oxygen therapy. Fundoplication surgery for gastro-oesophageal reflux disease was done at 17 months of age. Throughout his childhood and adolescence, he frequently missed school due to acute infections and multiple admissions requiring intubation. He recalled many discussions regarding do-not-resuscitate orders between doctors and his parents during each admission. He had never received PPC. **Discussion:** This case report highlights the missed opportunities for PPC during his childhood and adolescence. Facilitating important discussions with the child and the family could have improved their understanding, supported informed decision-making, and identified psychosocial and spiritual needs. Appropriate symptom management could have improved quality of life and reduced time off from school. Chest physiotherapy or occupational therapy could have improved his potential daily function. Respite care for his mother and other psychosocial interventions would help reduce overwhelming caregiver burden. **Conclusion:** Introducing PPC from the point of diagnosis could result in improved quality of life for PIBO sufferers. Clinicians should consider integrating palliative care approaches in the management of such cases.

**Keywords:** Paediatric palliative care, Bronchiolitis Obliterans, Multidisciplinary team
A DISTRICT LEVEL APPROACH IN FACILITATING THE TRANSITION OF CARE OF A CHILD WITH LIFE LIMITING POST INFECTIONOUS BRONCHIOLITIS OBLITERANS.

Vaishnavi Karunanithi*, Nurazzizu Ain Kamarul Zaman, Aina Mariana Abdul Manaf

Department of Paediatric, Hospital Port Dickson, KM 11, Jalan Pantai, 71050 Port Dickson, Negeri Sembilan, Malaysia

*Corresponding Author: Vaishnavi Karunanithi (ysh_k@hotmail.com)

Received: 3 November 2022; Published online: 26 November 2022

Abstract

**Background:** Post infectious bronchiolitis obliterans (PIBO) is a clinical syndrome characterized by the chronic obstruction of small airways which leads to permanent lung injury. Being a district hospital, providing sufficient care for this advanced life-limiting lung pathology has been a challenge. There are limited data and guidelines in managing the transition of care and maintaining a proper palliative care for PIBO patients at district level. **Clinical History:** A boy with underlying global developmental delay was diagnosed with PIBO at 2 years old. This child faced multiple hurdles due to his illness and family's poor socioeconomic background. His parents could not afford to provide the necessary equipment, long hospital stays and the 80 kilometros travel to the respiratory centre for his appointments. The psychosocial struggle caused familial disharmony and led to parental separation. This has increased the financial and social burden on the mother who is now a single parent. **Discussion:** The greatest hindrance was faced during the transition of care from acute hospital setting to community-based setting. Under the supervision of the respiratory centre, we mimicked their role at district level. The involvement of primary care clinic staff, the governmental and non-governmental organizations and family members helped to smoothen the process of transition. The result of this collaboration has optimized the care of the child and family greatly. **Conclusion:** The tertiary centre managing the child has been reassured that children with non-malignant palliative needs can even be managed at district level with good support and vigilant staff.

**Keywords:** Bronchiolitis Obliterans, Psychosocial, Transition of care
Abstract

Introduction: Non-verbal, severe neurological impairment children (SNI) may encounter multiple complex symptoms that significantly impaired the quality of their life. Dystonia is one of the commonest symptoms seen in these children. This could be one of the factors of pain or it could be triggered by pain behaviour in these children. Clinical History: Three (3) children (aged 2, 3 and 19 years old) with severe neurological impairment where their dystonia was difficult to manage were started on Gabapentin. Two (2) suffered from a brain tumour which was inoperable while the other one (1) suffered a non-cancer condition. With titration dosage of Gabapentin, the dystonia was better controlled with minimal side effects reported. Discussion: Gabapentin which is an anti-epileptic medication is used in the management of neuropathic pain and movement disorders in adults. Little is known about the effects in controlling dystonia in both adults and children. There are several studies internationally that report the benefit of Gabapentin in managing pain behaviour and dystonia in this group of children. However, till date, there are limited local studies that are published on the usage of Gabapentin for dystonia in children with severe neurological impairment. Conclusion: Gabapentin may significantly reduce dystonia as well as pain behaviour in children with severe neurological impairment. This overall helps to improve the quality of life in these children and their caretaker. This case series corroborated the observation of Hauer et al and Natasha et al in management of children with SNI.

Keywords: Gabapentin, Quality of life, Dystonia
Abstract

Objective: It is known that the general public has poor knowledge and a lack of appropriate understanding of the palliative care issue. The study was designed to explore public views regarding palliative care awareness in Northeast Malaysia. Methods: A cross-sectional study conducted on 78 caregivers of children admitted to Hospital Universiti Sains Malaysia. The standardized questionnaire consisted of a qualitative and quantitative component, which was distributed by 3 research assistants and collected from early December 2019 to the end of February 2020. Parents caring for children with life-threatening conditions were excluded. Results: The caregivers’ age range was between 18-30 (43%) and most were employed (61.5%). There were 59 females and 19 males. Only 52.6% had heard and 44.9% understood the meaning of palliative care. The level of awareness of palliative care was limited, with the majority of them reporting ‘never heard of it’ (47.5%). A small number (11.5%) of participants reported that they had a ‘vague idea’. Half of the participants had cared for dying relatives, and mostly they were family members. Majority preferred home (n = 68, 86.6%) as the place of care for terminally ill patients, followed by hospitals and other areas (n = 5, 6.7%). Conclusion: Despite differences in exposure to palliative care services locally, there was still insufficient awareness and understanding of the term palliative care.

Keywords: Awareness, Perception, Palliative Care
Abstract

Objective: With the introduction of palliative care national strategy in Malaysia last year, it is hoped that knowledge and attitudes towards palliative care will improve steadily. The aim of the study is to explore palliative care knowledge and attitudes among the caretakers of children in Northeast Malaysia. Methods: A questionnaire including demographic data, knowledge and attitude questionnaire was completed by 78 caretakers of children admitted to general Paediatrics ward at Hospital Universiti Sains Malaysia. Consent was taken prior to enrolment by the research assistants from December 2019 to February 2020. Inclusion criteria were parents or caretaker who understood English and those who have children without life-threatening conditions. Results: Approximately 70% of participants agreed that goals of palliative care were helping the families, managing pain, and providing emotional support. Significant number of participants (35-40%) were not aware of how to answer the attitude questionnaire; pointing to uncertainty to the questions posed. Similar to questions posed on attitude to morphine and death in hospice and dying, many participants (35-40%) answered as neutral reflecting uncertainty to answer the questions. Regarding the death and dying questionnaire, about one-third agreed on the need to relieve the suffering and having hope in the patients. And about 33% of them are also uncertain whether death can cause patients to lose hope. Conclusion: There is a need to widely educate the public to promote positive attitudes, enhancing understanding and strengthening the knowledge.

Keywords: Knowledge, Attitude, Palliative Care
Abstract

Background: Cryptogenic cirrhosis causes serious complications such as portal hypertension, gastropathy, and hepatic encephalopathy. Liver transplant is a treatment option for cryptogenic cirrhosis which offers improved survival and reverses complications of cirrhosis. Clinical summary: A 16-year-old girl was diagnosed with cryptogenic cirrhosis since age 12. She had multiple episodes of variceal bleeds since diagnosis, despite banding and sclerotherapy. The need for 6-monthly surveillance endoscopy and medications for portal hypertension resulted in great strain on her and her family. They lived in interior Sarawak, with limited access to tertiary healthcare services. Liver transplantation was never discussed with the patient and her family. She was referred to the family medicine specialist (FMS) for shared management and palliative care. The FMS discussed liver transplant and palliative care options with the patient and her family. She had no contraindications for liver transplant. The patient and her family were keen for referral for liver transplant after fully understanding its implications. Discussion: Holistic assessment of the patient’s needs, wishes and preferences is extremely important before discussing management options. Understanding their wishes and preferences for their treatment goals helps clinicians to ensure that all possible treatment options are discussed. This facilitates well-informed decision-making, particularly if treatment can reduce the patient’s symptoms and suffering. Providing supportive care concurrently with potentially curative treatment is consistent with the core principles of children’s palliative care. Conclusion: Clinicians should encourage open and unbiased discussion regarding goals of care and treatment options with the patient and family, to allow informed shared decision-making.

Keywords: Shared decision-making, Cryptogenic cirrhosis, Supportive care
REFERRAL TO PAEDIATRIC PALLIATIVE CARE SERVICE IN HOSPITAL SEBERANG JAYA AMONG PATIENTS WITH LIFE-LIMITING CONDITIONS DURING THE END-OF-LIFE

Teoh Yen-Lin*, Angeline Yeoh, Wong Wei Leng, Lee Wei Xin
Paediatric Department, Hospital Seberang Jaya, Jalan Tun Hussein Onn, Seberang Jaya, 13700 Permatang Pauh, Penang, Malaysia

*Corresponding Author: Teoh Yen-Lin (teohyenlin@gmail.com)
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Abstract

Introduction: Early identification and referral of children with palliative care needs may improve the outcomes by reducing distress, improving quality of life and ensuring appropriate measures during end-of-life care for both patient and families. Objectives: Describes the demographic of the paediatric palliative patients and to assess referral practice of general paediatricians and neonatologists to paediatric palliative care services. Methodology: Retrospective review of medical record of patients who died in general paediatric and neonatal ward in Hospital Seberang Jaya over a period of 72 months. Demographic data, clinical variables and patient circumstances during end-of-life care were examined. Result: A total of 168 deaths encountered among patients under care of paediatric teams in 2019-2021, most of them were patients from neonatal units (n=133). Two third of them (n=118) were patients with life-limiting conditions, the highest number recorded for genetics (30.5%), followed by neurology (21.2%) and prematurity (20.3%). More than half of them (n=94) were neonates with 62.7% died within 72 hours of life. Referral to paediatric palliative care (PPC) was lowest (6.3%) among neonates compared to 70% for general paediatric patients. Within the period of 2019-2021, total PPC referral was 82 with 35 deaths, 34% home death (n=12) and 14% of them (n=5) have resuscitation during end of life. Conclusion: Low neonatal referral could be attributed to their short life expectancy and under-utilization of paediatric palliative care service. Facilitated home death is possible with early introduction of advance care plans.

Keywords: Paediatric palliative care, End of life, Advance care plan
SHOULD COST BE CONSIDERED IN PLANNING WITHDRAWAL OF CARE OF REFUGEE?

Halimah Abdul Halim1*, Aliyyah Mohammad Khuzaini1, Siti Noor Munirah Ibrahim2

1Paediatric Department, Universiti Sains Islam Malaysia, Bandar Baru Nilai, 71800 Nilai, Negeri Sembilan, Malaysia
2Kasih Hospice Foundation, 16, Jalan SS 3/29, Taman Universiti, 47300 Petaling Jaya, Selangor, Malaysia

*Corresponding Author: Halimah Abdul Halim (halimah@usim.edu.my)
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Abstract

Objective: The cost of healthcare for refugees in Malaysia is expensive. Thus, refugees often seek medical attention late and become severely ill with poor prognosis, resulting in decision for palliative care. We explore the dilemma between providing the best of care to severely ill refugees with financial constraints despite imminent death. Methods: Patient 1 is an 11-year-old girl diagnosed with type 1 diabetes mellitus who presented late with severe diabetic ketoacidosis complicated with end stage renal failure. Renal replacement therapy was futile, and care was withdrawn after two weeks. Patient 2 is a baby born at 24 weeks of gestation and developed ventilator-dependent severe chronic lung disease. The mother had poor antenatal care. He succumbed due to nosocomial pneumonia. Patient 3 is a 6-years-old boy who presented with multisystem inflammatory syndrome in children, complicated with stroke and cerebral oedema. Care was withdrawn due to poor neurological prognosis at day 10 of admission. Results: Several ethical issues arise in these cases. Exorbitant costs are a deterrent to seeking medical care. Is this disparity in relative access to healthcare ethical? These patients may potentially survive had they sought earlier treatment. Secondly, when death is imminent, should cost be considered as a factor to withdraw care earlier? Should clinical decisions be influenced by the potential cost of caring for a disabled child? Conclusion: It is impractical and unrealistic to not consider cost when financial support is limited to refugees. However, this consideration should be made carefully ensuring care is not compromised or discriminated.

Keywords: Paediatric palliative care, Refugee care, Care withdrawal
**Abstract**

**Background:** Children who need palliative care may drool excessively, negatively impacting their quality of life. Botulinum toxin injections over salivary glands (BTISG), in addition to conventional pharmacological treatments, show promise in controlling excessive salivation. **Objective:** This paper aims to present the early clinical results of a service offering BTISG for excessive drooling saliva. **Methods:** Since 2019, the paediatric palliative unit at Hospital Tunku Azizah has offered BTISG for palliative patients with hypersalivation. Drooling Impact Scale and Drooling Severity and Frequency Score are used to assess patients before and after BTISG in Drooling Clinic. A paediatric interventional radiologist would administer the injections to chosen patients while using ultrasonography for guidance. A standard operating procedure guides the whole process, starting from criteria for patient selection, pre-procedure sedation, injection technique and monitoring of effectiveness and adverse effects post injection. **Results:** Since its introduction, a total of five BTISG has been performed for three separate patients. The patients had prior complications from hypersalivation such as recurrent cough and aspiration pneumonia. All patients had already used atropine and scopolamine patch prior to BTISG. All patients had reduction in drooling frequency after the first BTISG. Two patients had long term improvement in drooling frequency after one year. One patient deteriorated due to disease progression. There were no major complications of the procedure. **Conclusion:** BTISG can be a good option for severe uncontrolled drooling with a good safety profile at one year follow up.

**Keywords:** Palliative medicine, Interventional radiology, Child health
Objectives: Children with life-limiting illnesses have symptoms which can affect their quality of life and cause significant suffering. We aim to assess symptom burden in children with life-limiting illnesses. Methods: A prospective multi-centre cohort study of patients from palliative care services of six Malaysian hospitals. Self-administered age-specific Memorial Symptom Assessment Scale MSAS:7-12 (7–12-year-old) and MSAS:10-18 (10-18-year-old) were used in an out-patient setting. Children who were cognitively impaired were excluded. Results: From February 2020 to Jan 2021, there were 312 medical encounters from 48 patients. 56% of patients had cancer and 89% of whom were not on chemotherapy within 2 weeks of the survey. There were 133 MSAS:7-12 and 179 MSAS:10-18 filled. ‘Pain’ was the most common symptom from MSAS:7-12 with 48.7% occurring ‘Frequently’, it was ‘Severe’ and ‘Distressing’ at 64.1% and 46.2% respectively. Other symptoms perceived to be ‘Severe’ when present were ‘Tiredness’(58.1%), ‘Sadness’(55.6%) and ‘Worry’(58.8%). ‘Insomnia’(61.1%) and ‘Worry’(58.8%) were perceived to be ‘Distressing’ when present. From the MSAS:10-18, ‘Sadness’ was most common (53.1%) and perceived to be ‘Severe’ in 42.6% of the encounters. ‘Pain’ when present was ‘Severe’ in 79.6% of the encounters. Conclusion: Children living with-life-limiting illness experience both physical and psychological symptoms which can be severe and distressing. Healthcare providers need to be better prepared to assess and manage these symptoms.

Keywords: Symptom burden, Paediatrics, Palliative Care
Abstract

Objective: Palliative care has been a well-established service for patients with chronic illness. However, in the long haul of COVID-19 pandemic, it has been put on hold due to limitation of social contact. Disease and death during this pandemic have not only put patients through a painful process but healthcare workers for not being able to provide respite care. Methods: Simple questionnaire consisting of 15 questions assessing on knowledge, attitude and practice was distributed via google form to the staff in Paediatric Department Hospital Miri. Results: 76 responded (72%) to the questionnaire. 75% think that there is a palliative care plan and 61.8% think that we have a palliative care team. Majority (73.7%) disagree with the point that palliative care means giving up on a patient. 81.5% of the staff disagree that palliative care is not needed during this pandemic. Half of them expressed interest in learning more about this field and agreed on providing palliative care to non-Malaysian. In practice, they would discuss with the managing specialist. Only half of them feel challenging and stressful to handle palliative cases in ward. Conclusion: Palliative care provides comfort not only to patients but to healthcare providers. Proper guidelines and continuous education programs are needed to empower our staff on providing palliative care for our patients.

Keywords: Perception, Palliative care, COVID-19
Abstract

Objective: Managing palliative care in children is more challenging than in adults. This is particularly true for a child who was previously well present with sudden death be it from trauma or from a severe illness. The distress incurs not only affecting the family members but the managing team in the hospital. Case: G was a 2-year-old boy who was previously well referred to our unit for severe traumatic brain injury from a trivial fall. There was no evidence of blood dyscrasia nor history suggesting non accidental injury. 2 days later, he deteriorated and emergency decompressive craniectomy was performed. His condition remained the same after that and family were explained about the poor prognosis. His parents were hopeful and prayed for a miracle, refusing ‘no active resuscitation’ nor ‘no escalation of inotropes’. After prolonging his life to go through his 2-year-old birthday and allowing extended family visit, brain dead test was performed and eventually he died of a natural course. Discussion: Parental negotiation and hope in miracles have sometimes caused distress in health care personnel when there is a conflict between hope and reality. An ethics consult or facilitation could help reach some clarity for resolution. Repeated counseling involving multi discipline is important to make the parents come to accept the outcome. An ethics consult or facilitation could help seek better clarity and a resolution for stakeholders. Conclusion: Training and mental support for medical staff handling paediatric palliative care is essential in reducing moral distress among staff and family members.

Keywords: Moral distress, Parents, Ethics
Abstract

Objective: To study palliative care support among the caregivers in Kelantan during the COVID-19 pandemic. Methods: Cross sectional survey via an online questionnaire was distributed to caregivers of children with life limiting conditions. The instrument used consists of demographic details, subjective assessment of stress, and palliative care support. The invitation was sent anonymously to the clients of Sayang Homecare who lived in Kelantan from May to July 2021. Results: The total respondents were 64, with 70% of them being female. The mean age was 36.6, with the youngest caregiver of 18-year of age. Thirty four percent of the respondents were in full-time employment. Perceived high stress was seen in 28.3%. These were due to poor daily income, increasing daily COVID cases, lone caregiving, anxiety about an uncertain future, and family members. Main caregivers accounted for 76.6%. A large number (73.4%) received support in emotional (64.1%), spiritual (60.9%), and financial (45.3%) ways. The respondents admitted to experiencing health deterioration (32.8%). More than half (56.3%) of the patients still received palliative care support, which included physiotherapy (43.9%), medical (17.1%), nursing (14%) and psychosocial (17.1%), despite the COVID-19 pandemic. Conclusion: The perceived status of caregivers’ stress in Kelantan was high during the COVID-19 pandemic. There is a need to improve the service with a tangible plan to ensure adequate support for the caregivers and even the patients in the community.

Keywords: Palliative, Caregivers, COVID-19
Abstract

**Background:** Chronic pain is one of many challenges faced by children with palliative care needs and their family members. Management of chronic pain is complex and often involves addressing various biopsychosocial and spiritual issues. A regular clinic visit would be insufficient to handle all aspects of pain. **Objective:** This paper aims to present the preliminary clinical outcomes of a paediatric palliative chronic pain clinic (PPCPC) which provides holistic care for chronic pain. **Methods:** The PPCPC in Hospital Tunku Azizah started in 2019. It operated once per month with a professional team made up of paediatric palliative doctors, physiotherapists, occupational therapists, a psychologist, and nurses. Services provided by the team included pharmacological pain management, strengthening exercises, posture correction, activities of daily living modification, home visits, caregiver education, psychoeducation, and many others. Services are not limited to patients but are extended to their family members. The outcomes of this clinic were measured using the change in pain score from baseline and repeated during each session. **Results:** From 2019 till 2022, nine children have attended the paediatric palliative chronic pain clinic. Five were discharged to the regular palliative clinic after two to five sessions. Two had no more pain while the other three had reduced pain. One patient passed away while still under follow up. Three patients are still receiving this service. All patients were reviewed and jointly managed by the whole team. **Conclusion:** Chronic pain for a paediatric palliative patient is important and a holistic approach is needed to handle it.

**Keywords:** Palliative care medicine, Multidisciplinary team, Child Health
Abstract

**Background:** Spindle cell sarcoma is an extremely rare bone cancer. It is a soft tissue tumour usually found in the arm or leg bones, or in the pelvis. Treatment depends on the location and stage of cancer. Typically, treatment is done over a series of phases and includes chemotherapy, surgery, and radiation therapy. **Clinical history:** 16-year-old male child diagnosed with spindle cell sarcoma in left leg. Surgery was recommended, but the child-patient refused due to fear of death. Tumour grew in size and skin broke down, necessitating below-knee amputation followed by chemotherapy. One year later, he was diagnosed with pulmonary metastases. He was referred to our centre with swelling in the other leg, continuous severe pain, difficulty in getting up, pressure sore from lying down, and breathlessness. **Interventions:** 1) Regular home visits by a multidisciplinary team, 2) Physiotherapy: Improved mobility, wheelchair was provided, 3) Medical: Morphine administered for pain management; oxygen concentrator given to ease breathlessness, 4) Nursing: Dressing of pressure sore, air mattress provided for prevention, 5) Art and Recreation: Brought out creativity, kept him occupied and helped forget his pain, 6) Counselling: helped adolescent to express his emotions including body-image issues, immediate calming effect seen, 7) Family counselling: single mother’s challenges addressed; siblings helped to overcome drug addiction. **Conclusions:** Quality of life of child-patients and families can be improved through holistic interventions by a multidisciplinary team, even in advanced disease.

**Keywords:** Spindle cell carcinoma, Holistic intervention, Quality of life
Abstract

**Background:** Paediatric palliative patients spend most of their time at home. It is important that the home environment is conducive to their needs. Occupational therapists conduct home assessment while focusing on adapting environments, modifying tasks and teaching skills to ease daily activities. **Objective:** This paper aims to present the preliminary outcomes of a home assessment service conducted by occupational therapists for paediatric palliative patients. **Methods:** Home assessment services for paediatric palliative patients in Hospital Tunku Azizah started in 2019. There are four phases for home assessment, namely patient assessment, preparation, home visit and follow-up. On referral by paediatric palliative team, patients are assessed on actual physical capability and consent for visit is taken. Preparation phase involves preparation of administrative and technical issues. During the home visit, a home assessment checklist is used to ensure completeness of review and advice is given. The family is contacted after three months to follow up on the implementation of recommendations given. **Results:** From 2019 till 2022, there were a total of 12 referrals for home assessment, of which five (41.7%) home assessments were conducted. Four (33.3%) passed away before home assessment due to delay by the movement control order and three (25%) are still in the preparation phase. Main problems identified were difficulty to transfer patients, risk of fall, and furniture arrangement reducing mobility. These were solved by rearrangement of furniture and the provision of aids. **Conclusion:** Home assessment assists paediatric palliative patients in improving their home environment and quality of life.

**Keywords:** Palliative care medicine, Child health, Home visit
Abstract

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Conclusion: Home assessment assists paediatric palliative patients in improving their home environment and quality of life.

Keywords: Palliative care medicine, Child health, Home visit
Objective: Respite care is important for caregivers of children with medical complexity who face heavy caregiving burdens. This qualitative study explores the respite care needs among caregivers of children with medical complexity in two states in East Malaysia. Methods: This was a qualitative study conducted among primary caregivers of children with medical complexity recruited from two major hospitals in East Malaysia. Caregivers were purposely sampled for this study. Semi-structured in-depth interviews were conducted, audio-recorded and transcribed verbatim. Thematic analysis was done to identify salient themes related to their respite care needs. Results: A total of 17 primary caregivers were interviewed for this study. Themes included the impact of caregiving, the caregivers’ roles and responsibilities and influences on need for formal respite care. Caregivers had various roles and responsibilities towards their family, home, and work commitments besides medical caregiving for the child. Respite care would support caregivers to manage these roles and to provide time for personal self-care. Their need for formal respite care was influenced by availability of an alternative informal carer, the effectiveness of their own personal coping strategies, the child’s level of dependence on caregiving and their own level of trust towards other caregivers. Conclusion: Formal respite care may be needed by these caregivers if they lack the resources to cope with their caregiving burden. There is a need to develop formal respite care services to meet the needs of these caregivers.

Keywords: Respite care, Caregivers, Children with medical complexity
CASE REPORT: ANALYSIS OF NURSING PROCESS ON NASOPHARYNGEAL CANCER PAEDIATRIC PATIENT WITH PEACEFUL END OF LIFE THEORY APPROACH

Noor Siti Noviani Indah Sari*, Agung Trilaksono Pamungkas

Nursing Department, Dharmais Hospital National Cancer Centre, Indonesia

*Corresponding Author: Noor Siti Noviani Indah Sari (noorsiti.noviani@gmail.com)
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Abstract

Objective: Nasopharyngeal carcinoma (NPC) is a common tumour of the head and neck despite low incidence of NPC in younger age groups, it is the most common cancer with pain complaints among the children. The aim of this writing is to apply a peaceful end-of-life care nursing theory to NPC paediatric patients. Clinical History: We report a case of a 15-year-old boy with stage IV NPC with bone metastases. He presented with a painless palpable neck mass, nasal congestion, headaches and a history of occasional epistaxis. He also has complained of severe pain all of his body with a Numeric Range Scale is nine or ten. He was treated at Dharmais Hospital and analysed using Peaceful End of Life Theory. Results: This case report showed that the main nursing problem is chronic pain. Applying the theory of the peaceful end of life is appropriate for cancer paediatric patients with palliative conditions to improve their quality of life, free from pain, increasing feelings of comfort, peace, cherish, respect and feeling close to the parent or people who are meaningful in their lives. Conclusion: Pain management is an important concern for a child with cancer and every effort should be made to ease the pain during the treatment process. The theoretical approach focuses on the physical problems experienced and psychological, social, and spiritual needs. Nurses are expected to be able to apply the Peaceful End of Life theoretical approach in providing nursing care to paediatric patients with nasopharyngeal cancer.

Keywords: Cancer, Children, Pain
Abstract

**Objective:** To describe the characteristics of paediatric palliative care (PPC) consultation in Hospital Wanita dan Kanak-Kanak Sabah from January 2018 to June 2021. **Methods:** In this study, we observed characteristics of children from 0 - 18 years old whom PPC was consulted. We collected information on their age, citizenship, ethnicity, diagnosis, reason for referral and their outcomes. **Results:** A total of 311 children were consulted during this period with the majority of children coming from beyond the neonatal period (75%). In the neonatal period, congenital malformations and chromosomal abnormalities were the main diagnosis (36%). Beyond that, neoplasms (21%) and neurological disorders (19%) were mainstay. The highest reason for referral is for end-of-life planning (63%) followed by psychological support (18%) and symptom management (13%). **Conclusion:** This data gives us a better understanding of the challenges and needs of our local community to support PPC development.

**Keywords:** Palliative care, Paediatric, Tertiary
Abstract

Objective: To narrate the experience of establishing paediatric palliative care (PPC) in Hospital Ampang, a busy general hospital covering low to medium socioeconomic community. Methods: PPC service at Hospital Ampang was established in June 2020, consisting of medical doctors. Upon referral from the primary paediatricians, the PPC team holds a family conference to establish rapport and understanding of the PPC service. Subsequently, advanced care plan (ACP) and symptom care plan (SCP) are formulated together. If sudden death was imminent, a letter informing regarding the child’s life-limiting illness is issued, to ease the burial process. Upon discharge, a home visit is performed within a fortnight followed by regular home visits to monitor well-being, acute illnesses, and symptoms control. A designated telephone number is given to parents to contact should they have any concerns. They are then seen in the paediatric clinic every 3-6 months. Spiritual and psychosocial support are also offered to the parents throughout this process. Results: The service has cared for 12 patients fully with an additional 15 patients receiving input on specific issues such as ACP or symptom control. It is challenging to meet the demands of care with limited personnel and resources. Regardless, PPC has aided these patients to demise peacefully, many of them in the comfort of their homes. Conclusion: Children with chronic life-limiting illness have complex needs, different from the general population. A specialized service to manage these patients holistically is important to provide the best of care.

Keywords: Paediatric palliative care, District hospital, Services


**PAEDIATRIC PALLIATIVE CARE PROVIDERS’ CHALLENGE IN SYMPTOM CONTROL**

**Chong Lee Ai*, Yarsheny Sugumaran**

*Department of Paediatrics, University Malaya Medical Centre, Jalan Profesor Diraja Ungku Aziz, Lembah Pantai, 59100 Kuala Lumpur, Malaysia*

*Corresponding Author: Chong Lee Ai (leeai@yahoo.com)  
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**Abstract**

**Objectives:** We aim to explore the challenges faced by healthcare providers in managing symptoms in children with life-limiting illnesses. **Methods:** A mixed method study as part of another study on symptom burden in children with a life-limiting illness. 1) Data was collected from semi-structured interviews with palliative care providers from six hospitals on their challenges and analysed using thematic analysis. 2) Drug availability was carried out by a survey of WHO Model List of Essential Medicines for Pain and Palliative Care with the pharmacies of the six hospitals. **Results:** Analysis revealed two main themes: 1) Rapport and relationships with patients and parents 2) Supports for the provider and their service. The six sub-themes uncovered are 1) Collaborations with referring teams, 2) Referrals close to end-of-life, 3) Parental needs and decision-making styles, 4) Knowledge and skills of the provider, 5) Needs of an effective palliative care team and 6) Providers’ competing commitments. All hospitals had 7 of the 15 medications on the WHO essential list for palliative care. However, all hospitals had medications to manage common symptoms in palliative care, nociceptive and neuropathic pain, constipation, seizures, and vomiting. **Conclusion:** For paediatric palliative care to be integrated into health services, there is an urgent need for education and training to support the knowledge and skills of the generalist in palliative care. Increased awareness of palliative care amongst the local community will also improve care for patients and their families.

**Keywords:** Paediatric Palliative care, Symptoms, Education