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2ND NATIONAL CONFERENCE OF CHILDREN'S PALLIATIVE CARE MALAYSIA 2025

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ABSTRACTS

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OFFICIAL JOURNAL

PERCEPTIONS OF ADULT PALLIATIVE CARE PHYSICIANS ON THE TRANSITION OF PAEDIATRIC PALLIATIVE CARE PATIENTS TO ADULT SERVICES

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Abstract

Objective: This survey investigates adult palliative care physicians' perceptions of the transition process for paediatric palliative care patients moving to adult services in Malaysia. **Methods**: A descriptive cross-sectional study was conducted from May to June 2025. Adult palliative care physicians were invited to complete an online questionnaire developed from a literature review on transition challenges and provider preparedness in Malaysia. **Results**: Eighteen physicians participated (mean age 44.6 years), predominantly from the government sector (72.5%) with over 10 years of experience (66.2%). Half reported no formal transition training, and 44.4% identified transition age as 16 years or younger. Participants expressed inadequate preparedness and insufficient knowledge of paediatric-onset chronic conditions. Key barriers included limited interdisciplinary collaboration and inadequate community infrastructure to support this vulnerable population. **Conclusion**: The findings highlight significant gaps in infrastructure, provider preparedness, and multidisciplinary involvement, adversely affecting the quality of transitional care. Strengthening training, fostering interdisciplinary cooperation, and enhancing community resources are critical to improving transition outcomes for paediatric palliative patients.

Keywords: Transition care, Paediatric palliative care, adult palliative care multidisciplinary team, service

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CHILDHOOD MORTALITY WITH LIFE LIMITING ILLNESS BASED ON MALAYSIA NATIONAL MORTALITY DATA 2014-2022

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Abstract

Background: Paediatric palliative care (PPC) provides support for children with life limiting illness (LLI) and their family. PPC services is growing in Malaysia, but information on actual population need is lacking. Objective: This study aimed to estimate the number of children with LLI by using national mortality data. **Methodology:** A retrospective descriptive study using secondary data from Department of Statistics Malaysia (DOSM) was conducted on all paediatric deaths in Malaysia between January 2014 and December 2022. ICD-10 four-character-codes associated with LLI from previous studies were reclassified into three-character-codes, namely confirmed LLI codes or possible LLI codes based on whether all or some of the four-character-codes derived from the three-character-codes were LLI conditions. Confirmed LLI deaths (CLD) only included confirmed codes while possible LLI deaths (PLD) included both confirmed and possible codes. **Results:** During the 9-year period, there were 54,887 deaths among children aged 18 years and below. 48,492 (88.3%) were medically certified deaths, of which 5,537 (11.42%) were CLD and 22,100 (45.57%) were PLD. There was a median of 599 (interquartile range, IQR: 591-627) CLD and 2,416 (IQR: 2,335-2,535) PLD annually. For CLD, majority of children were from ICD-10 category "neoplasms" (2,499, 45.1%) and "congenital malformations, deformations and chromosomal abnormalities" (1,488, 26.9%). **Conclusion:** Almost half of the deaths amongst children may be attributed to LLI. PPC services can help to support these children and their family. However, many children with palliative care needs who are living were not included in this calculation.

Keywords: Child mortality, Palliative, Paediatric, Health service needs and demand, ICD-10

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EMPOWERING PARENTS: A CAREGIVER WORKSHOP FOR FAMILIES OF CHILDREN WITH SEVERE NEUROLOGICAL IMPAIRMENT

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Abstract

Objective: The primary objective is to identify the specific challenges encountered by families of children with severe neurological impairment (SNI), as well as to evaluate caregivers' competencies and confidence in addressing these challenges following participation in the workshop. **Methods:** The workshop was organized as a comprehensive one-day program with participants selected from a registry of patients with severe neurological impairment (SNI) actively receiving follow-up care at the combined neuro-palliative clinic. Pre-workshop online forms identified caregivers' key challenges, while post-workshop evaluations measured improvements in participants' skills and confidence following the training session. **Results:** Between October 2023 and March 2025, four workshops were conducted, involving 34 participants with diverse caregiving experiences. 27 participants completed the post-workshop feedback and reported that the workshops were highly beneficial and relevant to their daily caregiving routines. More than half (51.8%) reported an improved understanding of caregiving, while 37% especially valued the peer sharing sessions. Additionally, 14.8% gained confidence in Ryles tube insertion, 7.4% learned new physiotherapy techniques, and 3.7% found dental care sessions useful. Looking ahead, 15% wanted further training in physiotherapy and massage, and 11% were interested in learning more about emergency care and stress management. Others highlighted their desire for workshops on social welfare, advanced nursing, and pain relief strategies to further support their caregiving roles. **Conclusion:** In conclusion, the workshop meaningfully enhanced caregivers' confidence and practical skills. It also improved emotional and mental well-being, demonstrating the power of targeted educational support for families facing the profound challenges of severe neurological impairment.

Keywords: Caregivers, Neurological manifestations, Palliative medicine, Hospice care, Education

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EVALUATING THE EFFICACY AND SUSTAINABILITY OF THE NEW BEREAVEMENT CARE PLAN IN THE PAEDIATRIC DEPARTMENT, HOSPITAL SEBERANG JAYA OVER A 14 MONTH PERIOD

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Abstract

Background: Complicated grief affects up to 10% of bereaved individuals and 40% of bereaved parents, who often require psychosocial support. Bereavement care helps mitigate mental health risks in up to 50% of caregivers. However, only 23.6% of parents attended the pediatric bereavement clinic in 2023.
Objectives: This study aimed to evaluate clinic attendance after implementing an enhanced bereavement care strategy and assess the program's sustainability by identifying challenges faced by healthcare providers. Secondary objectives included assessing parental mental health using the DASS-21 questionnaire and evaluating satisfaction with the updated care model. **Method:** A retrospective cohort study was conducted at the Pediatric Clinic from April 2024 to May 2025. It involved bereaved parents whose children died in neonatal and pediatric wards. The revised care plan included a memory-making box (with footprints and photographs), bereavement pamphlets, and structured reminder calls. During clinic visits, parents completed the DASS-21 and a satisfaction survey and were offered supportive amenities. Healthcare staff completed an online perception survey. **Results:** Clinic attendance increased to 56%. Most healthcare workers viewed the revised model as beneficial and identified key barriers and solutions. Among parents who attended, the majority reported normal stress, anxiety, and depression levels, and unanimously described the session as helpful and satisfactory. **Conclusion:** These findings highlight the value of structured, compassionate bereavement interventions and support the long-term feasibility of an enhanced care model for grieving parents.

Keywords: Complicated grief, Bereaved parents, Bereavement care, Efficacy, Sustainability

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DEVELOPMENT AND PILOT TESTING OF A QUESTIONNAIRE ASSESSING CAREGIVER'S KNOWLEDGE, ATTITUDE AND PRACTICE ON OPIOID USE IN PAEDIATRIC PALLIATIVE CARE AT A TERTIARY HOSPITAL IN MALAYSIA

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Abstract

Objective: The purpose of this study to develop and pilot test a comprehensive assessment tool to evaluate knowledge, attitude, and practice (KAP) of caregiver on opioid use in children for pain management in Pediatric Palliative Care at Hospital Tunku Azizah Malaysia. **Methods:** This KAP of caregiver was a guided self-administered questionnaire and consisted of 17 knowledge, 9 attitude and 6 practice items. After items generation, it was assessed the content validity by an expert panel. The revised questionnaire was further pre–tested. This pilot study was a cross-sectional survey and recruited 35 caregivers from patient received opioid for pain treatment by PPC team in Hospital Tunku Azizah, Malaysia. Item analysis, construct validity and internal consistency were examined. **Results:** Two sub-domains were constructed for knowledge, three factor solutions for attitude and two factor solutions for practice domains respectively. All items retained in the questionnaire as the important of all items to be included. Internal consistency was good to excellent for knowledge (KR20 = 0.63), attitude (CA = 0.73), practice (CA = 0.64) domains. The finalized KAP caregiver questionnaire after analysis remained contained of 32 items with 17 knowledge, 9 attitude and 6 practice items. **Conclusion:** KAP caregiver was an adequately valid and reliable questionnaire which can serve as an assessment tool to evaluate the knowledge and beliefs among caregivers of patient received opioids for the pain management in Malaysia

Keywords: Caregivers, Health knowledge, attitudes, practice, Opioid analgesics, Paediatric palliative care, Pain management

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A COMPARATIVE STUDY ON THE KNOWLEDGE OF MEDICAL OFFICERS REGARDING ADVANCE CARE PLAN DISCUSSIONS IN HOSPITALS WITH AND WITHOUT PAEDIATRIC PALLIATIVE CARE SERVICES

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Abstract

Background: Advance Care Planning (ACP) is essential in paediatric palliative care (PPC), guiding treatment in line with family values. However, ACP is underutilized, especially in settings without formal PPC services. **Objectives:** To assess and compare medical officers' (MOs) knowledge of ACP in paediatric settings, identify perceived barriers, and evaluate self-reported confidence and experience in ACP discussions. **Methods:** A cross-sectional survey was conducted among MOs in six hospitals in Penang—two with PPC services and four without. A validated questionnaire measured ACP knowledge, barriers, and attitudes. Descriptive and inferential statistics were used for analysis. **Results:** MOs in PPC-supported hospitals had higher correct response rates on ACP timing (56.0% vs. 41.8%), components (68.2% vs. 53.7%), and ethical principles (36.4% vs. 25.4%), though differences were not statistically significant ($p > 0.05$). Key barriers reported included lack of training (88.7%), time constraints (68.4%), unclear hospital policy (64.7%), and fear of upsetting families (67.7%). While most MOs agreed that ACP improves quality of care (90.2%) and is a shared responsibility (93.2%), only 22.6% felt confident initiating discussions. **Conclusion:** Medical officers recognize the value of ACP but face significant knowledge and confidence gaps, especially in hospitals without PPC services. Targeted training and clearer institutional support are needed to improve ACP integration in paediatric care.

Keywords: Advanced care planning, Palliative care, Paediatrics, Terminal care, Health knowledge, attitudes, practice

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A DESCRIPTIVE REVIEW ON CHILDREN RECEIVING SPECIALISED PAEDIATRIC PALLIATIVE CARE AT HOSPITAL SHAH ALAM

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Abstract

Background: Specialised Paediatric Palliative Care service at Hospital Shah Alam (PPC HSAS) was established in keeping with the National Palliative Care Policy and Strategic 2019-2030. It delivers inpatient care and runs 2 monthly multidisciplinary team (MDT) clinics. Additionally, children and families are supported by Malaysian Children Hospice for home-based holistic care. **Objective:** This review describes the referral characteristics, symptom prevalence and role of MDT in specialised symptom management. **Methods:** Retrospective review on children receiving care under PPC HSAS aged 0-18 years from December 2023 until December 2024 was conducted. Data was extracted from the PPC database, department census and hospital electronic Health Information System(e-HIS). Data was recorded and analysed using Excel. **Results:** A total of 20 children (17 males, 3 females) with a median age of 6.5 years (range: 2 months to 17 years) received care. 90% lived within 15 km of the hospital and 85% had PaPaS score of ≥15. Neurological conditions were most common (55%), with pain (22%) and dystonia (19%) as prevalent symptoms. 65% had at least ≥3 symptoms. The MDT service addressed the physical, social, emotional and spiritual well-being of the children. Mean consultation duration for each patient was 24.4 minutes. At follow-up, 60% remained under care, 20% were discharged, 5% transitioned to adult services and 15% of families received bereavement support. **Conclusion:** MDT approach was seen as essential in addressing complex, multifaceted needs of children with life-limiting conditions and holistic support required by their families. Regular service reviews and further studies are needed to evaluate the outcomes of MDT interventions.

Keywords: Paediatric palliative care, Symptom, Specialised, Multidisciplinary, Family

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A DESCRIPTIVE STUDY ON PERINATAL PALLIATIV CARE SERVICES AT HOSPITAL TUNKU AZIZAH, KUALA LUMPUR

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Abstract

Background: Perinatal palliative care service (PPCS) provides support for infants and families when there is a diagnosis of severe life limiting illness either before or after birth. PPCS services have been established in Hospital Tunku Azizah, Kuala Lumpur (HTAKL) since March 2020. **Objective:** To describe the characteristics of referral and outcome of infants receiving PPCS at HTAKL. **Methods:** A retrospective observational study was conducted on all antenatal referrals for PPCS from March 2020 until February 2024. Data collected include referral information, clinical outcome, and services provided. **Results:** During the study period, PPCS received 29 antenatal referrals. Majority (89.6%) were Malay mothers. The median gestational age on referral was 32 weeks 3 days with the earliest being at 27 weeks 5 days. The main antenatal diagnoses were chromosomal abnormalities (11, 37.9%), abnormal brain or spinal cord development (4, 13.8%), congenital anomaly (4, 13.8%), and renal disorders (3, 10.3%). On delivery, there were 8 stillbirths. Among the 21 infants who were born alive, 4 died in the labour room while 10 died in NICU. The remaining 7 children were discharged home with feeding support and medications. Services provided by PPCS include labour room visit by PPCS team (7), family conference (8), anticipatory grief counselling (3), memory making (18), and home visit/hospice (3). **Conclusion:** PPCS supported families of infants with severe life limiting illnesses in navigating care, symptom management and bereavement support.

Keywords: Perinatal, Palliative care, Prenatal diagnosis, Family support, Life limiting

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THE USE OF THE PAEDIATRIC PALLIATIVE SCREENING SCALE (PAPAS) SCORE AS A ROUTINE SCREENING INSTRUMENT IN PAEDIATRIC ONCOLOGY PATIENTS: A SINGLE-CENTRE DESCRIPTIVE CROSS-SECTIONAL STUDY

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Abstract

Introduction & Objective: The Pediatric Palliative Screening Scale (PaPaS) Score is a screening tool used to determine the focus of care. Pediatric palliative care (PPC) is a vital component of pediatric oncology service, and the use of PaPaS may improve usage adherence and prompt provision of PPC. We conducted this study to assess the utilization of PaPaS score in pediatric hematology-oncology ward. **Methods:** This is a descriptive cross-sectional study conducted since August 2023. Data are obtained by medical record review of each inpatient episode from every patient with oncologic diagnoses. Patients with non-neoplastic diagnoses are excluded. PaPas Score is determined by on-duty hospitalist at the time of inpatient admission and authorized by the attending pediatric hemato-oncologist. A score of 10 or more indicated the need of consultation to PPC team. Data are reported using descriptive statistics, reported as median due to uneven distributions of data. **Results:** A total of 25 data points from 12 patients (5 females, 7 males) are included. The most common diagnoses are acute leukemias (75%), with other diagnoses including Burkitt's lymphoma, dysgerminoma, and neuroectodermal brain tumour. The median of the whole PaPaS score data points is 10, with 0 the lowest and 35 the highest data points, and 0 and 32 as the lowest and highest patient's personal PaPaS score respectively. 13 data points scored at least 10. **Conclusion:** Routine use of PaPas Score in pediatric oncology patients is integral and important to ensure that palliative care may be provided in a timely manner.

Keywords: Cross-sectional studies, Palliative care, PaPaS score, Pediatrics, Pediatric oncology

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THE BURDEN OF PALLIATIVE CARE FOR CHILDREN WITH CONGENITAL HEART DISEASE: A CARDIAC CENTER EXPERIENCE IN MALAYSIA

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Abstract

Objective: The aim of this review is to understand the burden of Paediatric Palliative Care (PPC) for complex congenital heart disease in a paediatric cardiac centre, Malaysia. **Methods:** This retrospective descriptive study examined all patient referrals to the Paediatric Palliative Care Service at Hospital Sultan Idris Shah (HSIS), Serdang, from January 2022 to May 2025. Data were extracted from existing hospital medical referral records. Descriptive statistics were used to analyze and summarize the characteristics of referred patients and referral patterns. **Results:** A total of 62 referrals were received, of which 58% were cardiac-related. The number of referrals has been increasing each year: 10 cases in 2022, 17 cases in 2023, and 24 cases in 2024. There were 11 referrals from January to May 2025. Among the cardiac patients, most have complex heart disease with no surgical options, inoperable residual lesions, cardiomyopathy, and severe comorbidities. The purposes of referral are mainly symptom management, advanced care planning, caregiver support, coordination of care across multiple specialties, equipment support, and discharge care. **Conclusion:** Despite the short duration of the pediatric palliative care service in HSIS, there is an increasing number of patients requiring palliative care. Advances in the diagnosis and treatment of patients with congenital heart disease have resulted in an overall decrease in mortality. However, these patients experience long-term morbidities and uncertainty in disease trajectory, thus requiring palliative support.

Keywords: Paediatric palliative care, Paediatric, Congenital heart disease, Paediatric cardiology, Palliative care

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COMMON MEDICATIONS USED BY NEUROPALLIATIVE CLINIC IN HOSPITAL TUNKU AZIZAH, KUALA LUMPUR

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Abstract

Background: Neuropalliative care in paediatric patients addresses symptoms that impact quality of life in children with severe neurological conditions which are life-limiting or life threatening. Optimal medication use is critical for symptom control and overall care. In 2019, neuropalliative service was introduced in Hospital Tunku Azizah, Kuala Lumpur (HTAKL), a children's and women's hospital. **Objective**: To present the common medications used by neuropalliative clinic in HTAKL. **Methods**: Patients with severe neurological impairment have many symptoms requiring pharmacological intervention. They receive multiple medications for a symptom, which compounds when a patient has multiple symptoms. Pharmacists play a role to reduce polypharmacy, prevent possible drug-drug interaction and reduce pill burden. **Results**: Eighty-six patients attended neuropalliative clinic from 1 May 2024 until 30 April 2025. Majority were boys (51.2%) and Malay (73.3%). Median age of patients was 11.0 years (Interquartile range, IQR 7.3-15.8). Patients received a median of 8 (IQR 6-9) different medications, with a maximum of 13 medications. Patients mainly required medications for seizure (94.2%), constipation (88.4%), dystonia (77.9%), gastro-oesophageal reflux disease (GERD) (67.4%), hypersalivation (36.0%), and insomnia (11.6%). Median number of concurrent medications received per symptom was 3 for seizure, as well as 2 for constipation, dystonia, and GERD. **Conclusion**: Neuropalliative patients receive many concurrent medications. All parties need to evaluate the need for each medication to ensure compliance, improve symptom control and reduce pill burden.

Keywords: Palliative medicine, Polypharmacy, Nervous system disease, Paediatric, Malaysia

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ADVANCED CARE PLANNING IN PAEDIATRIC PALLIATIVE CARE PATIENTS AT HOSPITAL TUNKU AZIZAH

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Abstract

Objective: Advance care planning (ACP) is an important process for children with life limiting conditions. It helps families and healthcare providers talk about values, beliefs, and wishes to guide medical decisions and future care but is not legally binding. **Methods**: ACP discussion by paediatric palliative care (PPC) team of Hospital Tunku Azizah (HTA) follows a structured, step-by-step approach. It focuses on eight parts: personal details, patient and family members involved in the discussion, diagnosis, symptoms and signs to expect during emergencies, personal resuscitation plan, end-of-life care preferences, preferences during life, and the agreement. Discussion starts by exploring what matters most to the child and family, followed by preferences for future care, and finally goals of care—ranging from full intervention to comfort-focused care. ACPs are reviewed 6-12 monthly or when the child's condition changes. **Results**: There were 83 deaths among paediatric patients referred to PPC team HTA between January 2024 and June 2025. ACP was completed in 69 cases (83.1%), while 56 (81.2%) of them had the latest review of ACP within one year of death. All families decided not for cardiopulmonary resuscitation and intubation. 98.6% had decided for maximum intensity of care in the general ward. 66 (95.7%) families had discussed preferred place of death. **Conclusion**: ACP coverage has room for improvement. Annual review and awareness of ACP are key to making ACP a normal part of children's care.

Keywords: Palliative medicine, Paediatric, Advance care planning, Cardiopulmonary resuscitation, Malaysia

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PREFERRED PLACE OF DEATH: PART OF ADVANCE CARE PLANNING FOR PAEDIATRIC PALLIATIVE CARE PATIENTS

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Abstract

Background: Preferred place of death (PPOD) is a key component of advance care planning (ACP) in discussions with families of children facing life-limiting illnesses during end-of-life care. **Objective**: To describe the preferred and actual place of death among patients under the Paediatric Palliative Care (PPC) Unit at Hospital Tunku Azizah (HTA), Kuala Lumpur. **Methods**: ACP discussions are a core aspect of managing patients with life-limiting illnesses within the PPC Unit at HTA. PPOD is addressed with patients and families when they are ready. Families opting for home death require community support from either hospice services or the domiciliary team. **Results**: Between January 2024 and June 2025, there were 83 deaths among patients under the care of the PPC Unit at HTA. Of these, 69 patients (83.1%) had undergone prior ACP discussions, and 66 (95.7%) had discussed their preferred place of death. Approximately half (51.5%) were undecided about the location. Among those who expressed a preference, 9 of the 11 who chose hospital death (81.8%) and 12 of the 21 who chose home death (57.1%) were able to fulfil their wishes. Of the 32 patients who died at home, 20 (62.5%) received support from hospice or domiciliary services. **Conclusion**: PPOD discussions are a vital part of PPC planning, aligning care with the values and preferences of patients and their families. However, some patients are unable to realise their choices due to various challenges. Strengthening community support and enhancing ACP implementation may increase the likelihood of fulfilling patients' and families' end-of-life wishes.

Keywords: Death, Advance care planning, Paediatric, Palliative care, Home care services

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PATIENT-CONTROLLED ANALGESIA BY PAEDIATRIC PALLIATIVE CARE UNIT IN HOSPITAL TUNKU AZIZAH

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Abstract

Background: Patient-controlled analgesia (PCA) can assist in better control of pain. Patients would get continuous infusion of analgesic and self-initiated immediate bolus of analgesic when needed. This is useful for children with palliative care needs because pain is one of their major symptoms. **Objective**: To describe the PCA service provided by paediatric palliative care (PPC) unit in Hospital Tunku Azizah (HTA). Methods: PCA services for uncontrolled pain was started by PPC unit HTA for oncology ward since 2019. It is guided by an existing standard operating procedure. Referred patients will be assessed for cognitive capabilities and competency in using the PCA machine. A medical assistant will set up the PCA machine based on settings from the PPC specialist. Patients are monitored for pain score and complications. PCA will be discontinued when pain is improved. **Results**: From 2021 till 2024, there were 11 patients who received PCA services. Median age of patients was 13.4 years (Interquartile range, IQR: 11.8-16.2), with the youngest being 8.9 years old. Majority were Malay (63.6%), male (54.5%), and in unstable phase (81.8%). All patients received PCA morphine. Median pain score improved from 8 (IQR: 7.5-8.5) to 0 (IQR: 0-2.5) with a median drop of 7 (IQR: 5.5-8). Side effects include nausea (18.2%), itchiness (9.1%), and urinary retention (9.1%), but did not cause PCA to be discontinued. Median PCA duration was 72 hours (24-120). **Conclusion:** PCA services by PPC unit HTA was able to improve pain score for uncontrolled pain with limited and acceptable side effects.

Keywords: Patient controlled analgesia, Paediatric, Palliative care, Chronic pain, Morphine

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OCCUPATIONAL THERAPY RECOMMENDATIONS FOR AIDS, ADAPTATION AND ASSISTIVE EQUIPMENT FOR PAEDIATRIC PALLIATIVE PATIENTS AT HOSPITAL TUNKU AZIZAH KUALA LUMPUR

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Abstract

Background: Paediatric palliative care patients experience problems affecting quality of life, which could be improved via aids, adaptations, and assistive equipment (AAA). Occupational Therapy (OCCT) providers assist by recommending AAA which support the children to achieve optimal functional independence and reduce caregiver burden. Despite its significance, there is limited data on OCCT recommendations and equipment implementation within the Malaysian hospital setting. **Objective**: To describe paediatric palliative patient referrals to Occupational Therapy (OCCT) in Hospital Tunku Azizah Kuala Lumpur (HTAKL) for Aids, Adaptive and Assistive Equipment (AAA) as well as the recommendations given. **Methods**: A retrospective descriptive study was conducted on paediatric palliative patients referred for AAA to the OCCT unit at HTAKL from January 2021 until December 2024. Data was extracted from OCCT census lists and from the electronic Hospital Information System. **Results**: There were 31 patients referred for AAA during the study period. Majority were male (54.8%), Malay (90.3%) and referred from the neuropalliative clinic (67.7%). OCCT recommendations and education was given for mobility aids (18), bathing aids (9), training adaptive devices (4), and toileting aids (1). However, only 17 (53.1%) of the recommended AAA were obtained, specifically 11 (61.1%) for mobility aids, 3 (33.3%) for bathing aids, 2 (50.0%) for training adaptive devices and 1(100.0%) for toileting aids. The majority of AAA obtained were funded by external sources (94.1%). **Conclusion**: The acquisition rate of recommended aids can be improved, highlighting the need for improved funding access and follow-up mechanisms to ensure timely provision.

Keywords: Occupational Therapy, Palliative, Paediatric, Activities of daily living, Self-help devices

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MEMORY MAKING USING FOOTPRINTS FOR PAEDIATRIC PALLIATIVE PATIENTS IN HOSPITAL TUNKU AZIZAH

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Abstract

Background: Memories and mementos could be important for families of patients with paediatric palliative care (PPC) needs, especially after the patients have passed on. The PPC unit of Hospital Tunku Azizah (HTA) assists with memory making through footprints using ink or clay. **Objective**: To describe the service of memory making by PPC unit HTA. **Methods**: During consultation sessions with patients and family, a choice of memory making through footprint is offered. The selection of materials or type of footprint is based on the age, size and clinical condition of the patient. Colour selection is based on the child's gender and parental preference. This footprint is designed by staff or by the family, with occasional additions of poetry written by the family members. Clay footprints take longer to be prepared, leading to longer duration before handing over to the family. **Results**: From November 2022 until June 2025, there were 52 episodes of memory making using footprints. Majority of patients were from paediatric cardiology discipline (27, 51.9%), Malay (37, 71.2%) and female (33, 63.5%). There were 51 ink footprints and 2 clay footprints produced. 2 footprints were made post-mortem. There were no major challenges during the making of the footprints. **Conclusion**: Footprint making is a feasible option for memory making.

Keywords: Palliative care, Paediatric, Advance care planning, Object attachment, Malaysia

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UNDERSTANDING THE PROFILE AND MOTIVATION OF VOLUNTEERS IN CHILDREN'S PALLIATIVE CARE: A DESCRIPTIVE STUDY IN MAPPAC

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Objective: This study aims to describe the demographic characteristics, interests, availability, and motivations of individuals who volunteer in children's palliative care services in Malaysia. **Methods**: A descriptive analysis was conducted based on volunteer registration data from 2023 to 2025, collected by the Malaysian Association of Paediatric Palliative Care (MAPPAC). Data included demographics (age, gender, location), type of volunteer interest, availability, relevant skills, work background, and reasons for joining. **Results**: A total of 205 volunteers were registered, predominantly female (82.4%), with the majority aged 30–49 years (58%). Most were from Selangor (48.8%) and Kuala Lumpur (23.4%). Volunteers expressed interest in general support (42.9%), homecare (23.9%), and events (26.3%). Preferred volunteering time was daytime (51.2%), with weekends being the most favored days (51.2%). Key skills included training & education (57.6%) and event organization (44.4%). Volunteers came from diverse work backgrounds, notably sales/marketing (11.7%) and NGO/charity (6.3%). Top reasons for volunteering were contributing back to society (50.7%), and gaining knowledge and experience (19%). **Conclusion**: Children's palliative care volunteers in Malaysia are predominantly women aged 30–49 with strong interests in education, events, and community service. Understanding their profiles and motivations helps tailor recruitment, training, and retention strategies, enhancing service delivery and volunteer engagement in pediatric palliative care.

Keywords: Palliative care, Paediatric, Volunteers, Hospice care

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THE LAST CHAPTER: EXPECTATIONS AND INSIGHTS ON END-OF-LIFE CARE FROM HEALTHCARE PROFESSIONALS

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Abstract

Objective: To explore the expectation and perspective of healthcare professionals on principles of good death based on TFHCOP (The Future of Health and Care of Older People) towards paediatric patients in Malaysia. **Methods**: We did a cross-sectional study on 50 medical officers working across Malaysia. We used a 15-questionaire questions based on the paper entitled: A good death: perspective of muslim patients and healthcare providers in which we compare the view of paediatrics medical officers and non-paediatrics medical officers. We used descriptive statistics to analyse the questionnaire responses. **Results**: More than 90% of Paediatrics Medical officers agree with the majority of the questions however we notice a lower percentage about 85% of non- paediatrics Medical Officers agree on the questions posed. Interestingly, both groups scored less than 70 % on question No.2 (To be able to retain control over what happens) and No.15 (A good death is a death accepted by the relative). **Conclusion**: This study highlights a broad consensus among Malaysian medical officers on key elements of a good death, with minimal variation between paediatric and non-paediatric professionals. Factors including limited exposure to paediatric patients and involvement in end of life care may be the reason for discrepancy among the two groups studied. Nevertheless, areas such as autonomy and family acceptance show less agreement, suggesting a need for further dialogue and culturally sensitive approaches in paediatric end-of-life care.

Keywords: Good death, Patient autonomy, End of life care, Palliative care, Malaysia

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"IN THEIR SHOES": UNDERSTANDING CAREGIVING NEEDS FROM PARENTS OF CHILDREN RECEIVING PALLIATIVE CARE IN OUR COMMUNITY

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Abstract

Objective: This study described the perceived caregiving needs from parents of children receiving palliative care in our community through services provided by the Malaysian Children's Hospices; focusing on physical, emotional, social, and practical support. **Methods**: A survey was conducted between 2nd December 2024 to 2nd January 2025, collecting feedback from caregivers of children receiving community palliative care support from the Malaysian Children's Hospices, regarding current services and other desired support. Thematic analysis was used to identify recurring needs and preferences. Caregivers of patients referred to 2 branches of MCH (Kuala Lumpur and Klang) from 1st June 2023 till 31st December 2024 were included. **Results**: A total of 20 responses were recorded and analysed. The majority of caregivers were involved with patients' care at home in between 6 to 10 years. The most frequently reported needs included home visits from healthcare professionals, access to medical equipment and care supplies, social welfare support, access to support therapies, and mobility/transport services. Caregivers also emphasized the importance of training and knowledge related to pain and symptom management at home, as well as opportunities for their children to engage in social interaction/therapeutic activities in child development and having access to respite care. **Conclusion**: Comprehensive and holistic support systems are essential for families caring for children with complex medical needs in community palliative care. Addressing the identified needs can improve the well-being of both caregivers and children, and promote better outcomes.

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PAVING THE WAY FOR DIGNITY IN HEALTH CARE FOR CHILDREN WITH SERIOUS ILLNESSES IN THE WEST OF NEPAL

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Abstract

Objective: To explore the perspective of children with serious illnesses (SI) and healthcare professionals (HCPs) on dignity in Nepal. To develop a Nepal-specific dignity model for children with SI and to develop a practical training module on dignity in healthcare in Nepal. **Methods**: In-depth interviews with 15 children (>12years), 15 caregivers ; and 4 focus group discussions each consisting of 8 HCPs in three hospitals in Gandaki Province using the guideline based on the dignity model for dying adults and the dignity model for terminally ill children. Recordings will be transcribed. The analysis will follow deductive (thematic) and inductive (grounded theory) processes to adapt and contextualize the previously developed dignity model in the Nepalese context. **Results**: Preliminary findings show empathetic communication, quality time and the attitude of HCPs play a major role in preserving dignity for these children. The HCPs have the realization that they fall short in providing care with dignity due to time constraints, set up etc. **Conclusions**: Despite the centrality of dignity in palliative care, there is little understanding in the healthcare context in Nepal. This study aims to explore the lived experiences of children with SI, their families, and HCPs to develop contextual model of dignity which will act as building block in developing training module for HCPs on caring for children and their families with dignity. It will further support in developing relevant policies and procedures

Keywords: Dignity, Children with serious illness, Pediatric palliative care

