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## **Growing Up Amidst Mortality's Shadow: Neuro-oncology Palliative Care For Adolescents and Young Adults in Sarawak, Malaysia A Case Report**

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### **Introduction:**

Neuro-oncology, particularly glioblastoma, remains challenging despite advancements, posing a significant threat to adolescents and young adults (AYA).<sup>1</sup> In Sarawak, Malaysia, the burden of care is amplified due to uneven palliative care coverage. Sarawak General Hospital serves as the primary referral centre, offering specialist oncology and palliative care services. Outside Kuching, cancer care, including palliative care, is provided based on tumour site by general surgical or medical departments. Much effort has been made over these two years to empower the 34 domiciliary palliative care teams across Sarawak to improve palliative care access.

### **Case Study:**

In AYA palliative care, literature gaps persist, especially in Asia, necessitating attention to unique challenges and age-related concerns.<sup>2</sup> Our case study of a 16-year-old male diagnosed with glioblastoma highlights these complexities. Initially presented with left sided upper limb and lower limb weakness and raised intracranial pressure symptoms. His rapid deterioration precluded curative treatment, prompting palliative care involvement for symptom management and support. Some of the themes that arose from his care included patient's emerging autonomy, loss of normalcy and home care support.

Discussion on end-of-life care underscores the importance of early, patient-centred conversations.

AYA patients, like adults, desire inclusion in decision-making and respect for their wishes.<sup>3-4</sup> In this case, the patient and parents were actively engaged, with tailored discussions as his condition worsened.

The patient's longing for normalcy, including school and home life, emphasises the impact of illness on daily living. Despite logistic challenges, the medical team went all out to fulfil his desires, such as arranging his schoolmates to visit in the ward and facilitating a home return to celebrate with family, albeit temporarily.

The preference for home-based care at end-of-life is evident, even amidst increasing symptom burden.<sup>5</sup> Collaborative efforts between family members and the palliative care team facilitated a memorable home visit, showcasing the importance of holistic, patient-centred care. However, this also highlights the disparity in palliative care access across different regions in Sarawak.

Challenges in administering equitable palliative care in Sarawak include access to medications, especially opioids, shortage of palliative-trained healthcare practitioners, lack of expertise in managing end of life care, insufficient awareness regarding total pain inpatients and insufficient recognition of grief and bereavement amongst family members.

### **Conclusion:**

Palliative care offers substantial relief in the face of glioblastoma's challenges, particularly for AYA patients. This case underscores the need for enhanced training and capacity-building to ensure equitable access to palliative care throughout Sarawak

### **Keywords:**

Palliative Care, Neuro-oncology, Adolescent

(Word Count - 400 words) \*Word count excludes title, author, headings and keywords

## **New Service of Palliative Care in HSIS, Serdang**

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### **Background:**

WHO has defined Palliative Care as an approach that improves quality of life for patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative Care is explicitly recognized under the human rights to health. There have been some challenges to expand the palliative service here in Malaysia since it was introduced back in 1991. Multiple factors have been linked including financial challenges and poor awareness of Palliative Care. In 2022, Palliative Care services in Hospital Sultan Idris Shah, Serdang started with inpatient consults service and this has been expanding ever since.

### **Objectives:**

To understand the needs for Palliative Care in a tertiary centre; to understand the roles of Palliative Care and the intervention strategies employed.

### **Methodology:**

This is an observational descriptive study and data collection was carried out in Hospital Sultan Idris Shah, Serdang from November 2022 to December 2023.

### **Results:**

Since Palliative Care service commenced in Hospital Sultan Idris Shah, Serdang, the total number of inpatient referrals to the Palliative Care Unit has increased gradually. There were a total of 71 inpatient referrals in 2022, whereas there were 552 referrals in 2023. The majority inpatient referrals to the Palliative Care Unit consisted of non-cancer cases (54.9%) as Hospital Sultan Idris Shah, Serdang is a non-oncology center. However, inpatient referrals for cancer cases still stood at 45.1% (n=281). Most of the inpatient referrals were unstable cases (39%). With better awareness of Palliative Care, more stable cases were being referred. Hence, stable phase cases comprised of 233 out of a total of 623, while deteriorating and terminal phase cases stood at 10.1% and 13.5% respectively.

552 Goals of Care (GOC) discussions were carried out and it covers health care decision-making in the context of clinical progression, crisis and poor prognosis.

### **Conclusion:**

Palliative Care can be helpful at any stage of disease and patients should be referred early on following a diagnosis of serious illness. Patients may benefit with different intervention strategies to improve their quality of lives. These include symptoms management, advance care planning, facilitating social support by referring to hospices and domiciliary care, bereavement support and supporting patients' family psychosocial and spiritual aspects. Hence, palliative care should be made accessible to all individuals.

### **Key words:**

palliative, consult, cancer

word count (391)

## **Terminal discharge in Hospital Tuanku Ja'afar Seremban: A retrospective study on its prevalence and outcomes.**

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NMRR: ID-24-01535-TJH

### **Background:**

Most patients with advanced illness often express their preference for home death during end-of-life care discussion. Being able to achieve their preferred place of death is considered a good death. Hence, for patients whose death is imminent (prognosis within hours to days), terminal discharge can be planned in order to fulfil hospitalised patient's wishes to die at home. This process includes caregiver education on end-of-life care as well as delivery of subcutaneous medications for symptoms management at home.

### **Objectives:**

To determine the prevalence and outcomes of patients receiving palliative care who underwent terminal discharge in Hospital Tuanku Ja'afar Seremban.

### **Methodology:**

The sample included all patients receiving inpatient palliative care who were terminally discharged from Hospital Tuanku Ja'afar Seremban, a state hospital in Negeri Sembilan, from January till December 2023. Retrospective data collection through daily census records and cross-checking with hospital EMR, *Sistem Pengurusan Pesakit*, were performed. Outcomes of the terminal discharges were obtained from respective community support that followed up on the patients.

### **Results:**

787 patients received inpatient palliative care in the year 2023 and of these, 64 terminal discharges were performed throughout the year. The most common age group that opted for terminal discharges was age range 70-79 years old (34.4%), followed by 60-69 years old (25.0%). The mean age was 66.9 (SD 14.0). There were slightly more females (56%). The ethnic groups were mainly Malay (65.6%), followed by Chinese (20.3%) and Indian (14.1%). Interestingly, there were more non-cancer diagnosis (53.1%) as opposed to cancer diagnosis. More than half were discharged from medical discipline wards (53.1%). Majority were supplied with subcutaneous medications for home use during terminal phase (96.9%) and all patients except eight were followed up by community support either NGO hospices or domiciliary services at Klinik Kesihatan. Almost 70% passed away at home within two weeks of terminal discharge, predominantly within the first week. 3 patients returned to hospital within a week and at least 2 of them had hospital deaths instead.

### **Conclusion:**

Terminal discharge is not a common procedure in hospital, however, often requested by family to be carried out for patients who had prior expressed preference for a home death. This meticulous process can be refined further to ensure a smooth transition for end-of-life care at home. More study is needed to examine pertinent factors that ease timely terminal discharges, prevent readmissions or emergency visits post discharge, and improve patient and family satisfaction.

### **Key words:**

terminal care, patient discharge, retrospective studies  
(394 words)

## **When The End Is Near: Drugs Utilization for Renal Palliative Care Patients in Palliative Care Unit (PCU), Hospital Selayang**

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### **Background:**

Patients dying from chronic kidney disease may experience distressing symptoms as their condition progresses. At the end of life, symptoms of discomfort are managed by pharmacological treatment. There is data for drug prescription at the end of life in the general population, however, limited research exists for renal palliative care patients, particularly within an Asian context.

### **Objectives:**

The aim of this study was to evaluate the drug utilization, including the types, dosage and route of administration for renal palliative care patients in PCU on the time of admission (Ta) and the time of death (Td).

### **Methodology:**

This retrospective cohort study was performed in Hospital Selayang PCU. All renal palliative care patients who died in PCU from January to December 2023 were identified and the relevant data extracted from the electronic medical records (EMR). The data included basic demographic information, type of drugs with the dose and routes of administration on Ta and Td.

### **Results:**

Among 43 eligible patients, 67.4% opted for conservative kidney management from the start, while 32.6% were withdrawal of haemodialysis from end stage renal failure. The median length of stay from admission to death was 6 days. The three most prescribed drugs on admission to PCU were fentanyl 69.7%, haloperidol 55.8% and midazolam 32.6%. At death, the prescription of fentanyl had increased to 72.1%, while haloperidol and midazolam had decreased to 51.2% and 27.9% respectively. The median daily dose of the top 3 drugs on admission were fentanyl 100mcg, haloperidol 1mg and midazolam 10mg. On the day of death, the median daily dose of fentanyl and midazolam had increased to 150mcg and 12.5mg respectively, while the dose of haloperidol remained unchanged. Fentanyl, haloperidol and midazolam were almost exclusively given via the subcutaneous route in both the time of admission (84.3%) and death (94.5%).

### **Conclusion:**

Fentanyl, haloperidol, and midazolam emerged as the primary medications prescribed at the end of life for renal palliative care patients, consistent with published data for the general population. The doses needed to optimize symptoms on the day of death are lower than in the literature. We hope to use this data to educate and train other healthcare providers in managing renal palliative care patients in their end of life. Further studies that include general palliative care populations can be done to increase the generalizability of our findings.

### **Keywords:**

Drugs Utilization, Renal Palliative Care, End of Life

(Word Count: 380 words)

## **Artificial nutrition and hydration in advanced cancer: values of patients, caregivers, and healthcare workers in Sri Lanka**

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**Local ethics approval obtained**

### **Background:**

Artificial nutrition and hydration (ANH) during end-of-life remains contentious, with variable practices worldwide. Understanding the practices and attitudes regarding ANH in Sri Lankan palliative care is required.

### **Objectives:**

We explored the values and preferences among patients, families and healthcare workers (HCWs) regarding ANH in Sri Lanka.

### **Methodology:**

Patients with advanced cancer (n= 12), family caregivers (current and bereaved, n= 15) and HCWs (doctors and nurses, n=22) underwent semi-structured exploratory interviews at the tertiary referral centre, National Cancer Hospital, Maharagama, to understand what mattered to them at end-of-life from cancer. ANH was also specifically discussed. Interviews were recorded, transcribed, and coded. Thematic analysis was performed.

### **Results:**

Artificial nutrition was primarily delivered through nasogastric tubes (NGTs). Patients generally had NGTs inserted before entering the terminal phase. NGTs were considered, by families and HCWs, as a practical need for administering analgesia.

Family viewed feeding as a practical need and a basic form of care. No intake was distressing to caregivers. Not delivering ANH was felt to be inherently wrong, and withdrawal of ANH was not acceptable. Caregivers did not report negative aspects of NGTs, unless asked.

Patient opinion was difficult to obtain directly. There were mixed views about artificial prolongation of life. When prompted, caregivers reported patient discomfort from NGTs, but that patients did not request removal of NGTs. Palliative care nurses felt patients generally preferred not to receive ANH.

HCWs faced the challenge of balancing the need to feed with their training on ANH, patient comfort and wishes, and opinions of others. Some felt delivering ANH was a basic duty, at least through artificial hydration. Receiving ANH at the end-of-life was not viewed by HCWs as contributing to a 'bad death'. The primary argument for continuing ANH was to meet family expectations. There was discomfort over withdrawing ANH, influenced by concerns about family perceptions. The standard practice was to deliver a slower rate of ANH, thus balancing family expectations with patient comfort. Palliative care nurses suggested that ANH and alternatives should be discussed, ideally earlier in the disease course, with patients and families.

**Conclusion:**

ANH is considered a basic form of care for patients with advanced cancer among family caregivers in a Sri Lankan setting, with NGTs considered a practical requirement by families and HCWs. HCWs have varying views on ANH. Providing ANH at a slower rate at the end-of-life is practised to balance family needs with patient comfort.

**Key words:**

Artificial nutrition and hydration, Sri Lanka, Cancer palliative care  
(Word 393)

## **Life beyond Loss: A Retrospective Analysis of the Pre and Post Brief Grief Intervention on the Grieving Process of Cancer Patients' Family Caregivers in Palliative Care.**

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### **Background**

The diagnosis of an advanced, incurable, and progressive cancer disease significantly affects both patients and their families frequently prompting emotional reactions such as sadness, anxiety, depression, guilt, anger, impotence, uncertainty, and fear. When faced with this reality, both the patient and their family are forced to (re)connect and (re)normalize as ways to bring a new meaning to this life event, living on a flux that, usually, leads them to confront human uncertainty, implicating an incessant ability to adapt.

**Objectives:** (1) to understand the family caregiver's perception on the adaptation to the end-of-life stage; (2) to evaluate the role of the family in the grieving process; and (3) to explore the aforementioned adaptation's role in the grieving process.

### **Methods**

We used the BGQ to screen for symptoms of complicated grief in English versions administered by Psychologist to 35 participants. The scale consists of 5 questions about difficulty accepting the death, grief interference in current life, troubling thoughts related to the death, avoidance of reminders of the loss, and feeling distant from others. Each item is scored from 0 to 2 (0=not at all, 1=somewhat, 2=a lot). The participants were spouses or closest family caregiver's to persons who being an inpatient (admitted) and outpatient to Palliative Care. Criteria for participating were being an adult living with the patient before and during the end-of-life process, and that minimum of 2 and a maximum of 4 months had passed since the patient's death.

### **Results**

Six themes were found: realizing that the partner would soon die, changing relationships, fear inducing feelings, focusing on doing the utmost for the sick partner, trying to live as usual, and time slipping away while also standing still. These themes were interpreted as aspects of grief: initializing grief, the emergence of grief, lacking the space to grieve, and holding grief at a distance, handling grief, and a temporality paradox of grief. Among the most salient aspects of this research was the finding that spouses often put their own feelings at distance, and endured suffering in silence. This suggests the need for support for spouses that not only aims to enhance their ability to facilitate the end-of-life situation for the sick partner, but also helps them to master their own lives.

**Keywords;** Family Caregivers, Grieving, Psychology of Palliative Care.



## Symptoms Management at Home: Addressing Patient Concerns and Compliance to Opioid

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**NMRR: pending**

**Background:** Opioid plays a crucial role in palliative care symptom management, including in the community, whereby most patients preferred to be cared for. However, concerns related to opioid misuse, addiction, and adverse effects often pose challenges in optimizing symptom management at home.

**Objectives:** This pilot study seeks to investigate the management of pain and breathlessness in patients at home. It also aims to examine the factors that influence compliance with opioid therapy. The study will also assess patients' adherence to laxatives to mitigate one of the common side effects of opioids, which is constipation.

**Methodology:** This pilot study utilizes a cross-sectional design employing a series of questionnaires administered by investigators to patients receiving opioid therapy in their homes. Inclusion criteria encompass all adult patients aged 18 and above undergoing opioid treatment and receiving care at the Palliative Care Unit of Sarawak General Hospital. Patient enrollment occurs between April 15th and 25th, 2024. A total of twenty patients enrolled to this study. The structured questionnaires were developed based on a review of literatures and input from palliative care experts concerning patient symptom management and concerns.

**Results:** A significant number of patients (60%, N = 12) expressed poor symptoms control at home, namely pain and breathlessness via a simple yes or no question. These were attributed to disease progression as documented in the oncology notes (92%, N = 11), constipation (58%, N = 7) and patient self-limiting of pro re nata "PRN" opioid doses at home (50%, N = 6). Among patients prescribed with regular opioid, adherence to dosing intervals were generally observed. However, there was a notable trend whereby patients did not take the PRN opioid doses or only took during severe pain episodes indicating a lack of proactive pain management. Despite most patients (60% N = 12) were able to report an extensive counseling covering most of the topics regarding opioid and laxatives, a substantial proportion of patients (50%, N = 10) continue to harbor fears and misconceptions about opioid. While patients recognize the importance of preventing constipation, laxative non-compliance was prevalent (65%, N=13).

**Conclusion:** This pilot study underscores the persistent presence of apprehensions and misunderstandings among palliative care patients regarding the proactive utilization of PRN doses of opioids and regular laxatives, consequently resulting in inadequate pain and breathlessness management at home. Hence, concerted efforts from healthcare professionals are necessary to deliver education and reassurance aimed at addressing these concerns.

**Keywords** Palliative Care, Analgesics, Opioid, and Compliance

## Talking About Dying : Assessing the Timeliness of Important Conversations in Advanced Cancer Patients

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### **Background:**

Effective communication is essential in palliative care for facilitating informed decision-making and can significantly impact patient satisfaction, treatment adherence, and quality of life. Studies have shown that patients and caregivers have high information needs at all stages of the disease process, including understanding the illness, anticipating future symptoms and their management, and prognostication. Discussing approaching death with patients is also crucial as it helps them participate in decisions about their care, set goals and priorities, alleviate symptom distress, and maintain a sense of dignity. Despite their importance, the frequency and nature of these discussions are not well documented, particularly in our local setting.

### **Objectives:**

To describe the number, content and timings of important conversations conducted with patients in a palliative care setting

### **Methodology:**

We conducted a retrospective manual chart review of all patients in Institut Kanser Negara who received an inpatient palliative care consultation for the first time between January 2024 and April 2024, and who passed away in the inpatient setting up to May 10, 2024. We report the duration between the initial contact by the palliative team and the date of death, along with an analysis of the important conversations held with patients and/or their family members during this period. We categorised the conversations into five types: i) illness understanding, ii) patient values and trade-offs, iii) goals of care discussions, iv) prognosis and expected decline, and v) acknowledging and communicating the dying phase. We examined the time interval between these conversations and the date of death to gain insights into the timing and frequency of communication in the palliative care setting.

### **Results:**

A total of 143 patients were included after exclusions. The median duration between the first palliative care consultation and the date of death was 4 days. 19 patients (~13%) died on the same day they were referred to palliative care. Conversations on prognosis and expected decline were conducted for 97 patients, with a median of 2 days between this conversation and the date of death. Of these, conversations were directly held with only 15 patients themselves, while the remainder were conducted only with their next of kin. We could only verify conversations about the dying phase in 75 patients (~52%).

### **Conclusion:**

Our findings indicate insufficient communication in terms of timeliness, content and participants involved in palliative care discussions.

### **Key words:**

communication, end of life, serious illness  
(397 words)

## **LAST MILE COLLABORATION : Bridging the Gap in Palliative Care Access to Essential Medicines**

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### **Background:**

Ensuring that palliative care patients can spend their final days in their desired location, which is often their hometowns, is a core component of compassionate care. Discharging patients to less central, resource-limited areas, however, can give rise to significant challenges in accessing necessary medications. This presentation illustrates the collaborative efforts required to overcome these challenges, presenting a small series of cases over the last 4 years.

### **Objectives:**

1. To demonstrate the vital role of collaboration among healthcare providers, community resources and family members in facilitating medication access for palliative care patients.
2. To discuss briefly the evolving landscape of palliative care infrastructure in less central / peripheral areas.

### **Methodology:**

A retrospective analysis and illustration of case studies involving our patients who wished to return to their hometowns for end-of-life care. These cases were selected based on the complexities of the patients' needs and the logistical challenges in ensuring timely and adequate medication provision. Each case demonstrates collaborative efforts across multidisciplinary teams to secure medication access.

### **Results:**

The case studies highlight the extensive lengths to which teams navigated logistical and bureaucratic hurdles to ensure patient needs were met. Despite geographical and infrastructural constraints, the effective collaboration between healthcare entities ensured that patients could spend their final days as they wished. Additionally, this presentation touches on recent improvements in the availability of specialist palliative care services closer to peripheral areas, which may reduce the need for such extensive coordination in the future.

### **Conclusion:**

These cases underscore the importance of strong, cooperative networks and the adaptability of palliative care services to meet patient needs under challenging circumstances. While recent developments and growth in palliative care offer hope for simpler processes moving forward, the lessons learned from these collaborations remain crucial in shaping future efforts in palliative care delivery. There is a need for continued advocacy for comprehensive palliative care services in all regions.

### **Key words:**

collaboration, access to care, medications, end of life, place of death

(318 words)

## ASCO THIRD PALLIATIVE CARE E-COURSE FOR MALAYSIAN HEALTHCARE PROFESSIONALS – PRE- AND POST-COURSE SURVEY

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### **Background:**

Palliative care training and education are very important to improve healthcare professionals' competencies in delivering holistic care. Since 2021, Sarawak General Hospital, University of Malaysia Sarawak, and American Society of Clinical Oncology have collaborated to conduct the ASCO Palliative Care e-Course (APCeC) program for healthcare professionals. In 2023, the third APCeC program included a more diverse group of participants from Sarawak, West Malaysia, and Indonesia.

### **Objectives:**

Educational objectives of the third APCeC program include:

- Understand the concepts and principles of palliative and end-of-life care.
- Communicate effectively with patients and their families.
- Safely and effectively use different medications to control pain.
- Better manage patient symptoms.

### **Methodology:**

The third APCeC program comprises 11 weekly virtual Zoom sessions from May 20th to September 9th, 2023. These sessions covered various aspects of palliative care using interactive case discussions and breakout sessions. Pre-course materials such as videos, PowerPoint notes, and articles were provided for self-study. Participants were asked to complete pre- and post-program questionnaires. The course's effectiveness was measured by improvement in the evaluation of objectives and the post-test results. The knowledge, competencies, concerns, and attitudes were measured by the differences in pre- and post-test questionnaire scores and point scale ratings.

### **Results:**

Most participants (n=85) were medical officers and nurses, with an average of 3.2 years of experience in palliative care. 18 participants (22%) have no palliative care experience. Participants were primarily medical officers (n=22, 24%), nurses (n=15, 16.7%), and palliative care trainees (n=9, 10%). This e-course achieved its educational objectives with the majority of participants reporting improvement in effective communication (94%), pain and symptoms management (93-94%), and understanding of principles of palliative care (94%). The average knowledge score also improved by 13.95%.

### **Conclusion:**

Overall outcomes suggested that the third APCeC program was successful. However, an impact assessment survey 6 months after the e-course will be more meaningful. Many participants gave feedback for more time and case-based discussion to improve subsequent courses.

**Keywords:** Palliative care, e-course, educational assessment. (316)

