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A retrospective study of Breathlessness Supportive Therapy on chronic refractory breathlessness in a palliative care unit

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Background:

Chronic refractory breathlessness is a debilitating symptom which negatively affects quality of life with profound impact on physical and psychosocial functioning of patients and/or carers. Multidisciplinary based interventions which focus on non-pharmacological approach have shown to be effective. We developed a breathlessness intervention service called Breathlessness Supportive Therapy (BST) in a palliative care unit with limited resources.

Objectives:

The aim is to evaluate the feasibility of developing a BST service and to study the characteristics and outcome of patients with chronic refractory breathlessness.

Methodology:

This is a retrospective study of patients with chronic refractory breathlessness and Modified Medical Research Council (mMRC) Dyspnoea Scale grade ≥ 2 who attended the BST clinic over 1 year period. BST consists of two clinic sessions 2 weeks apart. Data was retrieved from patients' medical notes and analysis done using Microsoft Excel.

Results:

21 patients were identified. Median age was 69. 52% females. 72% had non-malignant diagnoses. Median Charlson's Comorbidity Index score is 6.5. Median mMRC dyspnoea scale was 3. 47.6% had long term oxygen usage. Median Australian Karnofsky Performance Scale (AKPS) was 65 and the median baseline breathlessness Visual Analogue Scale (VAS) was 2. 62% completed 2 sessions, the remaining 38% completed only 1 session. Mean time from BST intervention to death was 18.26 weeks, median was 22 weeks. 72% died at home, whilst 28% died in the hospital. All patients scored 4 (somewhat agree) and 5 (strongly agree) on the overall feedback score.

Conclusion:

Development of a breathlessness intervention service is feasible in a resource limited setting and generally accepted by most patients. More research and prospective studies are needed to evaluate the effectiveness of BST in the future.

Key words:

Chronic refractory breathlessness, palliative care, breathlessness intervention service

(285 words)

**The body of this abstract should not exceed 400 words and this does not include spaces. Word count also excludes title, author, headings, keywords and NMRR.*

Demography and Outcome of Hospice Home Care Patients in Kuching, Sarawak - A Single Institution Experience

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Background:

Home is the preferred place of care and death for most patients with terminal illness, underscoring the importance of community hospice services. There is great disparity in access to hospice across Sarawak, and data regarding the demography and outcome of hospice patients in Sarawak is lacking.

Objectives:

To describe the demography and outcome of hospice patients with terminal cancer in Kuching, Sarawak.

Methodology:

We retrospectively reviewed the case notes of 544 patients with terminal cancer under our hospice care from 1st August 2016 to 29th February 2024. Data were collected under the following groupings: 1) demographics characteristics 2) details of terminal illness 3) duration of care 4) outcome of care.

Results:

A total of 544 patients were included comprising 47.1% (256) males, and 52.9% (288) females. The racial distribution was Chinese 67.8% (369), Malays 18.6% (101), Indigenous Sarawakians 12.7% (69) and others 0.9% (5). Mean age of the patients was 67 years old (range 22-94). 12.3% (67) of patients were below 50 years old. The 3 commonest cancers were lung (20.0%; 109), colorectal (17.8%; 97) and breast (10.7%; 58). Mean duration of care was 64.8 days (range 0-958). Majority (53.8%; 293) were under hospice care for less than 30 days with 35.8% (i.e ~ 1/3) being referred in their last 2 weeks of life. Of the 520 deceased patients, majority 84.6% (440) died at home (82.7%; 430) and nursing home (1.9%; 10) while 15.4% (80) died in hospital. 12 (15.0%) of these 80 patients stated hospital as their preferred place death and all had planned admission for end-of-life care. Care/ carer issue (64.7%; 44/68) was the main reason for re-admission for end-of-life care despite patients' wish to be home. Unplanned admission for hospice patients at end-of-life is uncommon (4.2%, 22).

Conclusion:

Sarawak boasts of a diverse ethnicity with majority of its 2.51 million population consist of indigenous Sarawakian (65.3%) widely distributed across vast remote regions, followed by Malays (19.3%) and Chinese (16.7%) mostly in the urban areas. Community hospice services are provided mainly by NGO hospices in few major cities in Sarawak. The study showed that with community hospices providing holistic support and access to essential medications, most patients can be palliated at home till end-of-life per their wishes. It highlighted issues with inequitable access to hospice care as well as late referrals due to lack of resources and awareness and supported the urgent call for more structured training and carer support throughout Sarawak.

Key words:

Hospice home care, Sarawak palliative care

(Word Count: 400)

Enhancing Palliative Care Delivery in a Tertiary Hospital: Establishing Palliative Care Link Nurses in Every Department

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Background: Palliative care delivery in a busy tertiary hospital setting often encounters obstacles that affect patients' comfort and overall quality of life.

Objectives: Bridging identified gaps in palliative care delivery at Sarawak General Hospital (SGH), a tertiary hospital. The gaps primarily involve medication errors, nurses' confidence levels in specific palliative care procedures, and the training burden on caregivers for medication administration and nursing care. To address these challenges, a multifaceted approach involving the establishment of Palliative Care Link Nurses (PCLNs) in every department was undertaken in December 2023 in SGH.

Methodology: SGH partnered with American Society of Clinical Oncology (ASCO) to improve palliative care, with 2 ASCO nurses visiting SGH for this purpose. A meeting on November 9, 2023, involved nursing managers to introduce PCLNs and plan to enhance palliative care. 42 PCLNs were appointed from diverse departments, mainly in leadership roles, ensuring broad representation across medical, surgical, and specialty units.

Results: PCLNs were assigned critical responsibilities, including ensuring proper pain and symptom management, educating caregivers, facilitating referrals to community palliative care, and collecting performance indicators for accountability. To bolster their competency, a series of workshops covering topics such as pain management, medication administration, communication skills, and career development were organized. Follow-up measures, such as WhatsApp groups and regular meetings, were instituted to support ongoing communication and training among PCLNs. Moreover, integration of a Palliative Care Ward nurse into interdisciplinary team weekly consultation rounds was established to enhance communication, understanding, rapport, continuity of care, and educational opportunities. Continuing nursing education (CNE) sessions were also conducted, inviting nurses from other departments to enhance their palliative care knowledge. A refresher course for PCLNs were planned 6 months after their appointment to explore and bridge their gaps in skills and knowledge.

Conclusion: In conclusion, the implementation of PCLNs in every department in SGH signifies a significant effort in improving palliative care delivery and ensuring every department takes ownership of palliative care delivery to their patients. By addressing identified gaps and empowering frontline healthcare providers, this initiative endeavours to enhance patients' outcomes, alleviate caregiver burdens, and cultivate a culture of excellence in palliative care within the hospital setting.

Keywords: Palliative Care Link Nurse, palliative care delivery, education and training

Developing a Community-based Palliative Care Model (CPCM) using a Primary Health Care Approach in Telangana, South India

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Background:

Palliative Care (PC) is an interdisciplinary approach that focuses on improving the quality of life for terminally ill patients. The community-based approach to delivering care has meant to improve patient outcomes while reducing the cost of care. However, in a low-middle-income country like India, the discipline is still in the infancy stage, requiring more attention to emerge as a multidisciplinary specialty. The statement aligns with the fact that PC is available to nearly 2% of the Indian population compared to 14% globally. Hence, this study aims to develop a comprehensive Community-based Palliative Care Model (CPCM) according to the cultural context and regional values.

Objectives:

The objectives of the study are to review and explore all the palliative care models available globally; to visit all the palliative care centers (government and non-government) in both the districts; to assess the essential resources available in the Health and Wellness Centers (HWCs), to conduct a knowledge, attitude, and barriers survey with the health-care professionals; to administer the POS (Palliative Care Outcome Scale) to the patients receiving palliative care along with identifying their challenges to receive the care; and to validate the developed model using Delphi technique.

Methodology:

A mixed-methods approach will be adopted for the three-phased study in two districts of Telangana. Phase I, a literature review, will be performed to explore globally available PC models, followed by an on-ground observational study. Phase II will address the gaps in existing models while identifying the unmet needs of the patients and caregivers. The outcome of the above phases will help develop a CPCM in Phase III.

Results:

The level of Knowledge, Attitude, Barriers, and Needs of the Healthcare Providers and patients will be identified to release the modified training modules and programs specifically for grassroots workers to help them assess and refer palliative care patients to the primary care setting from their homes.

Conclusion:

The new CPCM model, tailored according to the needs of the healthcare providers and patients/caregivers could be recommended at the policy level for the betterment of the unreached local population.

Keywords:

Palliative Care Model, Primary Health Care, India

A Descriptive Study of Children with Life-Limiting Illness Receiving Palliative Care under Malaysian Children's Hospice

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Background:

Malaysian Children's Hospice, established in June 2023 under the Malaysian Association of Paediatric Palliative Care (MAPPAC), offers home-based paediatric palliative care services.

Objectives:

This study aims to describe patient demographics, referral characteristics, and services provided by Malaysian Children's Hospice.

Methodology:

A retrospective review of patient case notes, utilizing electronic medical system (EMS) and physical documentation, conducted for individuals aged between 0 and 18 years referred to Malaysian Children's Hospice (located in Kuala Lumpur, Sibul, and Klang) from 1st June 2023 to 31st March 2024.

Results:

A total of 103 patients were registered under the Malaysian Children's Hospice. The majority (28.0%) of patients were primary school children aged 7 to 12 years old. Significantly, most patients (96.1%) were referred by government hospitals with a low socioeconomic background. Among the referrals, the majority of patients had diseases of the nervous system (31.1%), which coincides with the primary referral team from the neurology department (44.7%). Nurse home visits remain the major clinical service provided (93.2%), as the majority (90.3%) of patients required support from home medical devices. There were a total of 18 (17.5%) deceased patients, 88.9% of whom had at least one home visit in the last 7 days of life. 17 (94.4%) patients had discussed advanced care plans (ACPs), with 11 preferring home death, of which 10 achieved it peacefully.

Conclusion:

The Malaysian Children's Hospice predominantly receives neurology referrals from government sectors. Through hospice support, patients are able to achieve peaceful home deaths. There is a clear need for increased advocacy in children's hospice services across various departments and within the private healthcare sector.

Key words:

Children, Palliative Care, Hospice

(264 words)

Keeping Mum About Mom: Cancer Diagnosis Disclosure in a Cognitively Impaired Patient -An Ethical Dilemma

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Background:

Although cognitive impairment amongst cancer patients is becoming increasingly prevalent in ageing societies, however, the impact of disclosing cancer diagnosis in cognitively impaired individuals remains understudied.

Objectives:

This paper explores the ethical considerations surrounding disclosing a breast cancer diagnosis to an elderly patient with cognitive impairment.

Methodology:

This is a case report of an 88-year-old Malay woman, partially dependent in activities of daily living (ADL) and scoring 12 on the Mini Mental State Examination (MMSE), presented with a growing mass in her right breast. Subsequent diagnosis revealed invasive ductal carcinoma (cT4bN1Mx, ER/PR negative, HER2 +3). Her family declined further staging and opted for palliative care. Following a month, she returned with breast ulceration and underwent elective palliative radiotherapy. Upon discharge, her condition worsened steadily over the ensuing month. She was then readmitted for community-acquired pneumonia with concomitant lung metastasis. She improved with antibiotics and analgesics but remained bedridden after being discharged. Throughout her medical journey, her diagnosis remained undisclosed, and she sought medical attention only at the insistence of family members, though she maintained a cheerful demeanour during clinic and hospital visits.

Results:

Cultural factors play a significant role in diagnosis disclosure and its effects on patient well-being. In Asian cultures, patients unaware of their diagnosis have been observed to report better quality of life, albeit confounded by variables such as family support and financial stability. Additionally, Asian family members often opt to shield patients from such knowledge. In this study, the decision to withhold the cancer diagnosis was made with the ethical principle to “do no harm” as its basis, based on evidence that suggests patients with lower MMSE scores regarded decision-making as a burden rather than a privilege. Moreover, recognizing that cognitively impaired patients undergo similar grief processes as those without impairment, non-disclosure was deemed potentially less detrimental to her overall well-being.

Conclusion:

Disclosure of cancer diagnosis is a delicate dance between multiple ethical principles, and even more complex in patients with cognitive impairment. Physicians must be mindful of such scenarios when managing patients to avoid a decline in their mental well-being.

Key words:

Breast Cancer, Palliative Care, Cognitive Impairment

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The roles of palliative care societies and challenges faced by them in Perak State, Malaysia

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Objectives:

To analyse the roles and challenges faced by palliative care societies in Perak State, Malaysia.

Methodology:

Descriptive and analytical study by analysing social media reports, annual reports and WhatsApp messages.

Body:

As population longevity increases, changes in dietary habits, unhealthy lifestyles, contaminated environments, and surroundings have led to an exponential increase in cancer cases leading to increase in the end-of-life patients and terminally ill populations. The role of palliative care societies in the present time has gained significant importance to answer these needs. Palliative care societies act as a bridge between the public and private hospitals and terminally ill clients to lessen their end-of-life sufferings. Dedicated doctors, nurses and volunteers play a significant role in this area. In Perak, there are three palliative care societies in Ipoh, Taiping and Manjong. There is no dedicated terminally ill hospice in Perak yet. These societies are doing a wonderful job in ensuring terminally ill patients do not suffer more and ensure they have a substantial pain free end of life. Home visits, giving of medicines, referral to hospitals, counselling family members and carers, changing of dressing and other procedures are their basic tasks. The society also lends oxygen concentrators, hospital beds, wheelchairs, suction pumps, commode chairs, rollator walks, and food baskets to the needy ones. Creating public awareness through campaigns, health exhibitions, public forums and collaboration with other government and non-government agencies is done. Organizing charity food and fun fairs, charity dinners, festive cheers, collecting donations from generous donors is also done. Regular discussions, case studies, educational visits to other hospitals are also done. The major challenges faced by the society is manpower, money, machines, and materials. The staff strength is not enough to manage new cases. There is a rapid turnover of staff due to the better offer from private sector. The staff who come here are semi-retired, unable to find better jobs elsewhere or those wishing flexible working hours. The staff attrition issues are a major problem. Remuneration is a long-standing grouse. This depends on the incomes derived from government grants and donations. Nurses need cars to do home visits. Maintenance of vehicles is expensive. Another major challenge is having a big building to store all the equipment's. Staff burnout and respite care are common issues. At times differences of opinions between management committee and staff arises. With all these challenges, the services rendered by the palliative care societies in Perak is very commendable.

Results:

This societies in Perak are facing a lot of challenges in terms of manpower, staff attrition, high patient demand and burnt out symptoms.

Conclusion:

This study confirms the presence of challenges and roles of palliative care societies in Perak

Key words:

Keywords: Palliative care society, home care, staff attrition.

(372 words)

End-of-Life Care Decision-Making for Adult Intensive Care Unit (ICU) Patients: A Comparative Study of Malaysia and the UK

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The end-of-life decision making process for incompetent adult patients in ICU is a complex and ethically charged issue that demands careful consideration. In Malaysia, a multicultural and multi-religious society, diverse beliefs, values, and cultural norms significantly impact end-of-life care decisions. In addition, the decision to try to keep a dying patient alive for an extended period has significant repercussions for the patients themselves, as well as for their families, those who depend on them, and the medical professionals who care for them. This doctrinal research explores the present legal framework in Malaysia and compares the Mental Capacity Act (MCA) 2005 in UK that emphasis on patient autonomy and principle of informed consent as guidelines by MMC are not legally binding. This comparative analysis highlights the cultural, ethical, and legal nuances that shape end-of-life care decision making in both countries. By exploring the experiences and perspectives of key stakeholders in both countries, this research aims to contribute valuable insights into the field of healthcare ethics and policy promoting improved end of life care decision making practices for critically ill patients. Shared decision-making should be a default management to all incompetent patients in ICU. Future research in this area should focus on the development of culturally tailored interventions and policies to enhance the decision-making process and promote a dignified and compassionate end-of-life experience. Understanding this variation is crucial for healthcare professionals in both Malaysia and the UK to provide patient-centered care and support during their challenging phase of end-of-life care. It is essential to highlight that Malaysia has no explicit mental capacity laws. The attending physician, who serves as the head of medical staff, is responsible for determining whether the proposed course of action is reasonable. The only explanation is that society has not yet fully embraced Advanced Medical Directives and that there are still many contentious issues around it because of varying political, societal, cultural, and legal viewpoints.

Keywords: End-of-Life Care, Incompetent Patients, Shared Decision-Making, Advance Directives

Compassionate Care in the Final Lap

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Background:

Hippocrates, the father of medicine, once said “to cure sometimes, to relieve often, to comfort always.” In the era of modern medicine where the primary goal is to clinically treat and cure, comfort is often diluted in the vast care plan. Palliative care which is a critical branch of medicine, ensures that comfort is part of the prescription. In this narrative case write up, the objectives of palliative care were clearly demonstrated through the service provided by Hospis Malaysia, to our dear family member.

The Power of Palliative Care

In the story of the late YT, a 76-year-old female with progressed Acute Myeloid Leukaemia, a wonderful lady who had fulfilled all her roles in life with such grace, palliative care offered her a dignified departure that she deserved. The moment Hospis Malaysia became part of the care team, a pain free solemn transition was ensured. The alleviation of suffering in her final lap created an environment conducive for objective decision making and family closure.

The Hospis nurses truly played a mediatory role on top of performing as competent care providers. The ability of the Hospis nurses to conduct an objective interview with the patient helped unveil individual final wishes and desires which further facilitated decision making with family members. Apart from addressing the needs of the patient, Hospis elevated the role of family members by training them to administer basic clinical care such as wound dressing and medication administration.

Outcome:

The personalized service provided by Hospis Malaysia brought comfort not only for the patient, but also for the patient's loved ones. It enabled a peaceful passing of YT. The dignified and divine nature of her passing made it more acceptable for her loved ones to witness, transforming an otherwise tragic event into a spiritual phenomenon.

Conclusion:

Palliative care provides a holistic approach that considers the physical, psychological, social, and spiritual aspect of a person in their final lap. The services provided by Hospis Malaysia needs to be very well supported in order for the organization to be sustainable and benefit all those who are and will be in need.

Key words:

Palliative care, compassion, comfort