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Inter-organisations collaboration helps meet end of life goals in patients with terminal illness - The Kuching, Sarawak Experience

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Background:

Most patients with terminal illness in Sarawak and Malaysia prefer to die at home but lack of continuity of care and paucity of community hospice support are barriers to achieving this goal. In August 2016, the palliative care unit at Sarawak General Hospital (SGH) together with local NGO hospices piloted a collaborative model of care enhancing inter-organisations collaboration and bi-directional communication between hospital based palliative care unit and community-based hospice teams.

Objectives:

To describe demographics and end-of-life outcome of hospice patients registered with Palliative Care Unit, SGH and referred to two community hospices in Kuching, Sarawak.

Methodology:

Case notes of patients under two NGO hospices in Kuching between 1st August 2016 till 29th February 2024 were retrospectively reviewed.

Results:

A total of 1298 patients were studied, of which 46.5% (603) were men and 53.5% (695) were women. 98.1% (1273) had terminal cancer. The racial distribution was Chinese 60.9% (791); Malay 23.7% (307); Indigenous Sarawakian 14.6% (190) and 0.8% (10) others. Elderly 70 years old and above accounted for 44.8% (582) of the patients, while those under 40 years old were 4.2% (55). Mean duration of care is 98.9 days (range 0.5-1001days). The 3 most common cancers were lung 18.8% (239), colorectal 16.6% (211) and breast 10.9% (139). Majority 81.0% (1017 out of 1255) of the patients died at home vs 15.2% (190) in hospital and 3.8% (48) in nursing home. Care issue was the main reason for re-admission to hospital for end-of-life care 51.6% (98), followed by symptoms control 28.4% (54), patients' preference 18.4% (35) and Covid infection 1.6% (3).

Conclusion:

Hospice care is patient and family centred care and requires good team work. Inter-organisations collaboration allows palliative care providers from different organisations to work together to identify needs, share resources and evaluate outcome collectively. This study showed that most patients with terminal illness in Sarawak can die at home per their wishes with good support. Collaboration and team work between hospital based palliative care unit and community-based hospice teams augment continuity of care and help achieve patients' goals at end-of-life. With training and support from leadership, this collaborative care model can be adapted to and implemented by hospitals and community healthcare clinics and domiciliary teams across Sarawak to ensure equitable access for every patient who needs palliative care and help meet their end-of-life goals. Inpatient hospice, carer support and caregiver training are unmet needs that call for urgent attention and evaluation.

Key words:

End-of-life goals, Collaborative model of care, Inter-organisation collaboration

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National Cancer Institute Oncology Palliative Care Model: From Start Till the End and Beyond

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Background:

The three components of a fully integrated palliative care program are an inpatient consultation service, outpatient practice, and geographic inpatient unit. All three serve different but complementary functions to support patients/ families through the illness experience, potentially from diagnosis till death and bereavement.

Objectives:

To describe the model of palliative service within an oncological center.

Methodology:

A literature review was done to research on different models of palliative care services in oncological centers.

Results:

The model of service is based on the integrated care model where the oncologist can refer patients to specialist palliative care teams early in the disease trajectory. This standardizes patients' access to timely and comprehensive palliative care concurrent with oncologic care and normalizes the introduction of palliative care. The palliative and supportive care team consists of a multidisciplinary team of doctors, nurses, a pharmacist, clinical psychologists, a counsellor, occupational and physiotherapists. This allows a holistic management of patient's palliative needs from a biopsychosocial point of view, from point of diagnosis till death and bereavement.

Conclusion:

Various domains have been identified to further strengthen its capacity, i.e adequate staffing, staff wellness, availability of service, continuity of care and education. Challenges and future ambitions include strengthening capacity to accommodate staff attrition and turnover, increase geographic coverage of home services and increasing quality care in the spiritual domains.

Keywords: Oncology Palliative Care

Use of Eye Tracking Device and its Association with Quality of Life in Motor Neurone Disease: A Case Report

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Background:

Motor-Neurone-Disease (MND) is a progressive degenerative disorder that leads to the destruction of the upper and lower motor neurons in the body, resulting in muscle weakness. This weakness gradually spreads to encompass all voluntary muscles but typically spares the eye muscles, allowing the use of eye-tracking-devices (ETD).

Objectives:

We report on the use of the Tobii-Pro-Fusion (ETD) and its impact on the quality of life (QOL) of a patient using the Amyotrophic-Lateral-Sclerosis Specific-Quality-of-Life-R (ALSQOL-R) tool

Methodology:

Retrospective review of patients' medical record under the care of a community palliative care organisation

Results:

A 41-year-old woman diagnosed with MND was introduced to the use of Tobii-Pro-Fusion when she developed bulbar weakness. Using the Amyotrophic-Lateral-Sclerosis Specific-Quality-of-Life-R (ALSQOL-R) tool before and after using Tobii Pro Fusion; she exhibited improvements in quality of life (QoL) across various domains. Specifically, there were notable enhancements in the domain of negative emotions (average score from 2.92 to 5.23), interaction with people (4.09 to 6.90), and physical symptoms (0.83 to 5.83). Additionally, there were increases observed in the domains of intimacy (average score from 4.43 to 6.29) and bulbar functions (1.4 to 5.2). The average total QoL also improved significantly from 3.54 to 6.23.

Discussion:

The ALSQOL-R, a valid ALS-specific global QOL instrument, assesses six domains: negative emotions, interaction with people and the environment, intimacy, religiosity, physical symptoms, and bulbar symptoms. It measures a patient's perceived outcome and is freely available for public use. Lower scores in negative emotions may indicate the need for further evaluation for depression, anxiety, concerns about the future, and coping ability. Similarly, lower scores in interaction with people and the environment signify lesser satisfaction with life and perceived social support. High intimacy scores suggest a strong desire for and experience with various expressions of intimacy. Furthermore, high objective functional measurements may correlate with low scores in physical and bulbar symptoms and viceversa. This case report underscores the importance of using ETD to enhance the quality of life for MND patients. The device appears to boost patients's social interaction, community participation, and autonomy in care decisions

Conclusion:

The use of ETD improves the quality of life of individuals with MND. However, further prospective and larger-scale studies need to be conducted to fully understand its efficacy and impact.

Keywords:

motor neurone disease, eye tracking device, patient-perceived outcome

Occupational Therapy Utilization in Palliative Care Unit, Hospital Selayang in Malaysia: A Descriptive Study

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Background:

Physical needs of palliative patients come in different forms. As their life-limiting illness progresses, they tend to have reduced ability to remain active and maintain function. Enabling and maintaining meaningful activities are part of a holistic approach to maintain quality of life thus supporting them to live with dignity. The role of occupational therapy (OT) as part of a specialized palliative care team is to assist patients with physical function assessments and specific interventions.

Objectives:

Our aim is to describe the utilization of the different occupational therapy services in the palliative care unit in Hospital Selayang.

Methodology:

A cross sectional descriptive study was performed using an existing dataset longitudinally collected by occupational therapists on referrals from palliative care unit to occupational therapy service in Hospital Selayang from Jan 2019 to Mac 2024. A detailed dataset of patient demographics, diagnosis, reasons of referral and services were collected from October 2023 until March 2024 after an introduction of a new data collection system. Descriptive data was extracted, reviewed and analyzed.

Results:

In 2019 there were 218 new palliative cases referred with total encounters of 1062 in the year. Subsequently, the number declines with referral ranging between 106-158 cases. In 2023, new cases referred were 114 cases with the total encounters of the year being 380 contacts. In the last 5 years most frequently reported OT services required by palliative patients were patients' and carers' education (27.0%), motor function assessment/training (24.1%) and ADL Assessment & training (21.7%). In the 6 months between Oct 2023 and Mac 2024, more than half of the patients referred are male (51.6%) with the median age of 70 with Interquartile range 15 (60-75). In the same period, there were 98 new cases referred and 59 of them (60%) were malignancy cases. Most malignancy cases were colorectal (25%), Lung (11.8%), Breast (8.5%) and Prostate (8.5%). CKD is the commonest non malignancy referral (38%).

Conclusion:

Occupational therapy plays an integral part of an interdisciplinary team in palliative care with the primary role of physical function assessments, offering specific interventions and providing education.

Key words:

Occupational therapy, Palliative care, ADL

(349 words)

End-of-Life Care of a Deaf Patient: A Caretaker Perspective

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Background:

As hospice and palliative care services strive for inclusivity and cultural competency, it is essential to explore the unique challenges and considerations involved in caring for individuals with diverse communication needs, particularly Deaf individuals. This narrative explores the journey of a caretaker who navigated hospice and palliative care with a Deaf partner during his end-of-life stage.

Objectives:

This narrative aims to raise awareness, foster understanding, and stimulate dialogue within the hospice and palliative care community regarding the unique needs and experiences of Deaf individuals approaching the end of life.

Methodology:

The author employed a self-narrative approach, drawing on personal observations, reflective journaling, and in-depth reflections conducted throughout the end-of-life caregiving period.

Results:

The author discusses the challenges encountered while providing care for the Deaf patient. These challenges included communication barriers and the limitations of hospice and palliative care services in Sarawak. While palliative care doctors and nurses proficiently managed physical pain, the lack of counselors or medical social workers added unspoken burdens in addressing the emotional distress experienced by the patient and caregiver. The narrative highlights the critical role of empathy and cultural sensitivity among healthcare providers in delivering person-centered care for Deaf individuals at their final stage of life. The caretaker emphasizes that effective communication is a fundamental component of quality care, particularly for Deaf patients. Due to the lack of qualified medical social workers or counselor and culturally aware medical staffs, the emotional and psychological challenges faced by the patient and the caregiver were not addressed. Additionally, the narrative highlights the importance of involving Deaf individuals in discussions about their care preferences and ensuring they have access to support services that cater to their specific needs.

Conclusion:

This presentation seeks to promote inclusivity, enhance cultural competence, and inspire compassionate care practices that honor the dignity and autonomy of all individuals. By bringing up the voices and experiences of caregivers, this narrative aims to inspire meaningful change and foster a more compassionate and equitable approach to end-of-life care for all, especially the population with special needs. Addressing these gaps can lead to improved care outcomes and a more supportive environment for Deaf individuals and their families during the hospice and palliative care journey.

Key words:

Deaf patient; hospice and palliative care; cultural sensitivity