

ABSTRACTS FOR ORAL PRESENTATION

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Exploring the experiences and end-of-life care preferences of Malaysian patients with advanced cancer.

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Background

Despite the growing interest of advance care planning (ACP), little is known about the experiences and care preferences of patients with advanced cancer in Malaysia, in contrast to developed countries. ACP and end-of-life care discussions are especially challenging in conservative Asian communities due to the taboo surrounding death, yet remain essential especially among patients with advanced cancer. It is important for healthcare professionals to better understand the local perspectives of Malaysian cancer patients in order to provide patient-centred and goal-concordant care.

Objectives:

To explore qualitatively the experiences and preferences of Malaysian patients with advanced cancer.

Methodology:

Semi-structured, face-to-face interviews based on the topic guide adapted from the Serious Illness Conversation were conducted with individuals with advanced cancer at the National Cancer Institute, Putrajaya from July 2019 to February 2020. Patients with stage 4 cancer were recruited from various backgrounds via purposive sampling in order to attain a variety in age, ethnicity and religion. Interviews were conducted in Malay, English or Cantonese.

Results:

A total of 19 participants (10 females) completed the interviews. Data saturation was achieved with the 17th participant. The participants were Malay (10), Chinese (6) and Indian (3), with an age range of 23-67 years. Majority (14) resided in urban locations. All completed at least secondary school level of education and eight completed tertiary education. Through thematic data analysis, three major themes arose: 1) Varying ways of dealing with poor prognosis. 2) Spirituality as a source of strength. 3) Enablers of advance care planning.

Conclusion:

This study revealed a spectrum of experiences and preferences among Malaysian patients with advanced cancer. Participants described different ways of dealing with their diagnosis and prognosis. Our data revealed key findings of spirituality and family as important factors in overall coping, achieving acceptance and willingness to engage in ACP. Although healthcare professionals should always assess each patient's preferences when it comes to prognostic information and ACP discussions, it is important to recognise the role of family and spirituality in this local context. The involvement of family in ACP and better integration of spiritual care into mainstream healthcare services may be helpful to improve the healthcare experience of Malaysian cancer patients.

Keywords:

advance care planning, spirituality, qualitative research
(352 words)

Factors Influencing Resilience in Patients with Terminal Illnesses: A Cross-Sectional Study

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Background:

Patients with advanced cancer or chronic organ failures often have “total pain” where physical decline can accentuate psycho-existential distress. Resilience is crucial in helping these patients to cope with adversity, but limited information is known about factors influencing it.

Objectives:

This study aimed to explore physical, psycho-social and spiritual factors influencing resilience in patients with terminal illnesses.

Methodology:

This was a cross-sectional study on 64 patients admitted to palliative care unit, Hospital Queen Elizabeth Hospital from May 2023 to February 2024. Data were collected using a demographic data collection form, Integrated Palliative Outcome Scale (IPOS), FACIT-Spiritual Well-Being (FACIT-Sp-12), Hospital Anxiety and Depression Scale (HADS), Brief Resilience Coping Scale, Brief-Coping Orientation to Problems Experienced Inventory (Brief-COPE). Factors influencing resilience were analysed using SPSS.

Results:

Majority of the patients had advanced cancer (88%) while 14% had chronic organ failures. The mean Brief Resilience Scale was 14.81 (SD 2.65), with one third reported low resilience(score<14). Coping strategies had significant positive correlation with resilience includes positive reframing ($r=0.47$, $p<0.001$), acceptance ($r=0.30$, $p=0.02$), religion ($r=0.32$, $p=0.01$), active coping ($r=0.54$, $p<0.001$). Spiritual wellbeing ($r=0.48$, $p<0.001$) was also associated with greater resilience. Denial ($r=-0.34$, $p=0.01$), behavioural disengagement ($r=-0.4$, $p<0.001$) and self-blame ($r=-0.38$, $p=0.002$) showed significant negative correlation with resilience. Anxiety ($r=-0.308$, $p=0.002$) and depression ($r=-0.388$, $p=0.002$) were also associated with low resilience. Impact of physical symptom burden on resilience did not reach statistical significance($p=0.06$).

Conclusion:

Coping styles and spiritual wellbeing had significant influence on patient resilience in facing terminal illnesses. Spiritual care support and development of adaptive coping skills can help build resilience in this group of patients.

Key words:

Resilience, Terminal Illness, Coping style

(272 words)

Factors leading to high caregiver burden in patients with terminal illnesses: a cross sectional study

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Background:

Patients with terminal illnesses often have complex physical, psychosocial and spiritual needs. Caregivers frequently bear the responsibilities to provide for these needs with little known about their care burden.

Objectives:

This study aimed to explore caregiver coping and burden in looking after patients with terminal illnesses.

Methodology:

This was a cross-sectional study on 108 primary caregivers of patients admitted to Palliative Care Unit, Queen Elizabeth Hospital from May 2023 to February 2024. Data were collected using demographic data collection form, Zarit Caregiver Burden Scale (ZBI), Big Five Personality Inventory-10 (BFI-10) and Brief Coping Orientation to Problems Experienced Inventory (Brief-COPE). Factors influencing caregiver burden were analyzed using SPSS.

Results:

The mean Zarit Burden Interview (ZBI) score was 27.06 (SD 13.61). Majority of caregivers reported mild to moderate burden (43%) whereas 18% reported severe burden. ZBI score was significantly higher among caregivers who were next of kin compared to distant relatives or formal caregivers ($p=0.002$). Neurotic personality ($r=0.37$, $p<0.001$), venting ($r=0.42$, $p<0.001$) and denial ($r=0.26$, $p=0.01$) coping styles were associated with significantly higher ZBI score.

Conclusion:

Caregiver relationship, coping styles and personality traits were found to have significant association with caregiver burden. Empowerment with more adaptive coping styles may help to reduce burnout in high risk caregivers.

Key words:

Caregiver burden, terminal illness, coping style

(205 words)

The Relationship between Spiritual Well-being and Health-Related Quality of Life among Cancer Survivors in Home-based Palliative Care.

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Background:

Cancer survivors receiving home-based palliative care often encounter unique challenges that affect their health-related quality of life (HRQoL). While the importance of spiritual well-being (SpWB) in influencing QoL is acknowledged in cancer care, its specific impact on cancer survivors under home-based palliative care remains underexplored, particularly in the context of Kerala's community-based palliative care movement.

Objectives:

This study assesses the relationship between SpWB and HRQoL among cancer survivors receiving home-based palliative care in Kozhikode district, Kerala, India.

Methodology:

A cross-sectional study employing multi-stage cluster sampling was conducted among cancer survivors in Kozhikode district, Kerala, India. SpWB was measured using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale, version 4 (FACIT-Sp12, v. 4), encompassing Meaning, Peace, and Faith subscales. HRQoL was assessed using the Functional Assessment of Cancer Therapy-General scale (FACT-G, v. 4). Statistical analyses included descriptive statistics, Pearson correlations, independent sample t-tests, Kruskal-Wallis, and Mann-Whitney U tests.

Results:

Two hundred cancer survivors participated in the study, with a majority being female (63.00%), aged 50 years or older (78.50%), and living with their spouse (65.00%). The mean age was 58.57 (SD = 10.52). Most participants (97.00%) reported a 'religious perspective' regarding their perception of God, and 93% practiced in religious rituals. A significant positive correlation was found between HRQoL and SpWB ($r = 0.707$, $p < 0.01$).

Conclusion:

This study adds valuable insights into the relationship between spiritual well-being and the quality of life of cancer survivors under home-based palliative care. This topic has not been extensively studied in the context of community palliative care in Kerala, India. Understanding this relationship can help healthcare providers develop more holistic approaches to care that address the spiritual needs of cancer survivors, ultimately improving their overall quality of life.

Keywords:

Spiritual well-being, Health-Related Quality of life, Palliative care, Home care, India.

What is a good death in South Asia? A systematic review and narrative synthesis

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Background:

Approximately 9.9 million people in South Asia live with serious health-related suffering. To deliver palliative care, it is important to understand what a 'good death' means to the relevant people. Such studies have mostly occurred in Western settings.

Objectives:

This study aimed to increase understanding of what a good death is considered in South Asia.

Methodology:

A systematic review with narrative synthesis was conducted. The search was performed on eight databases ('good death' and 'South Asia'), an advanced Google search and bibliographies of selected texts. No date or language limits were applied. Empirical studies on a good death from the perspective of any adult stakeholder were included. Quality appraisal was performed.

Results:

25 studies were selected (10 quantitative, 14 qualitative and 1 mixed methods), from India (n=17), Pakistan (n=4), Sri Lanka (n=2), Bangladesh (n=1) and Bhutan (n=1). There were no studies from the Maldives, Nepal or Afghanistan.

Four themes emerged. *Mutual care and connection support a continued sense of self*: contributing to others, while receiving connection through relationships and spiritual practices, was important for patients and supported by families and healthcare workers. *Freedom to choose- privilege or burden?*: the choice to participate in care was necessary for some patients but a burden for others, who preferred the family to lead their care. Severe uncontrolled pain and financial distress precluded choice for some patients, who felt death was the only option. Decisions regarding artificial prolongation of life were complex for patients and healthcare workers. *Opportunities in the last days*: when actively dying, there was general agreement on the importance of being pain-free, feeling safe and having family present. Home was not always the preferred place of death. For family, it was critical to perform last rites. *After death matters*: what happens after death – influenced by leaving a legacy and religious beliefs- affected all parties before, during and post-death.

Conclusion:

To the best of our knowledge, this is the first review of what a good death means in South Asia. More studies regarding this topic are required. Although the South Asian perspective has similarities with the Western perspective, we note important nuances around decision-making moderated by culture, religion, and poverty. Ongoing work is required to provide good symptom management, thus increasing opportunities for patient participation in care. Further research is needed in areas of ethics and religion at the end-of-life in South Asia.

Key words:

Good death, South Asia, Systematic review

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