

CONFERENCE ABSTRACT

Mobilising Local Resources around Integrated Palliative Cancer Care in Indonesia

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Introduction: A growing need for palliative care in Indonesia is a result of increased life expectancy and the incidence of chronic diseases including cancer. Although palliative care for cancer patients has been sporadically available in Indonesia, continuity of care and the integration of palliative care throughout the cancer trajectory is lacking. The research explored the current scope and status of palliative care in Indonesia and what might be required for the development of effective integrated palliative care in Indonesia.

Methods: The research methods were underpinned by the interactionist and structural assumptions of pragmatism, symbolic interactionism and structuration theory. The study participants consisted of three groups: adult cancer patients receiving palliative care and their family caregivers; healthcare professionals involved in palliative care; and policymakers in the area of palliative care. Semi-structured interviews and policy documents were the primary data sources. Interviews were conducted with 12 cancer patients, 14 family caregivers, 11 policymakers and 23 healthcare professionals. Data generation was conducted across sites in Jakarta, Indonesia, including hospitals, government departments and homes of patients and carers.

Results: The analysis process produced two key conceptualisations: owning patients and mobilising local resources. The medical model dominated cancer care and posed barriers to early referral to palliative cancer care and to multidisciplinary teamwork in the provision of cancer and palliative care. Care for patients with cancer was fragmented and largely focused on the treatment of pain and other physical symptoms. Harmonising services reflected an evolving if imperfect, integrated palliative care system built by NGOs and community groups to address obvious gaps in the continuity of care across health care facilities. In the absence of palliative care policies, an emergent informal system used existing health care structures to link services and social media to communicate and coordinate palliative care among various palliative care providers. This ground-level network maximised limited resources for the benefit of palliative cancer patients. While all key stakeholders recognised and appreciated the informal community-based palliative care system, only a small fraction of cancer patients were being supported by this system.

Conclusion: In the absence of effective Indonesian government policy, an informal model of integrated palliative care has evolved alongside the dominant medical model of palliative care. The work of NGOs and community groups provides a starting point for policy development and application to expand integrated palliative care for cancer patients in this country.

Lesson Learned: An informal grassroots system of integration of palliative care may be an effective way to start to integrate palliative care in the health care system.

Limitations: This study was conducted in one area in Indonesia. However, the generated concepts can be used as a basis for palliative care policies development in Indonesia.

Suggestions for Future Research: Further research on the grassroots processes underpinning NGOs and community-integrated care structures may provide a template for government policy development in this area.