

Utilizing intricate care networks: An ethnography of patients and families navigating palliative care in a resource-limited setting

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Abstract	<p>Background: The increase in non-communicable disease burdens and aging populations has led to a rise in the need for palliative care across settings. In resource-limited settings such as Indonesia, however, notably in rural areas, there is a lack of professional palliative care. Little is known about specific palliative care navigation, as previous studies have mostly focused on cancer care navigation. A locally tailored approach is crucial. Aim: To explore how patients and families navigate palliative care and the problems they experience. Design: An ethnographic study using in-depth interviews and observations, analyzed using reflexive thematic analysis. Setting/participants: Interviews with 49 participants (patients, family caregivers, and health professionals) and 12 patient-family unit observations in Banyumas, Indonesia. The analysis: Patients and families navigated palliative care through different strategies: (1) helping themselves, (2) utilizing complementary and alternative medicine, (3) avoiding discussing psychological issues, (4) mobilizing a compassionate and advocating community, and (5) seeking spiritual care through religious practices. Conclusions: Our participants used intricate care networks despite limited resources in navigating palliative care. Several problems were rooted in barriers in the healthcare system and a lack of palliative care awareness among the general public. Local primary health centers could be potential palliative care leaders by building upon pre-existing programs and involving community health volunteers. Cultivating a shared philosophy within the community could strengthen care collaboration and support.</p>
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