

"Tie your camel first, then rely on God": reconceptualizing Javanese Islamic values to support palliative care at home

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Abstract	<p>Background In the last decade, there has been a growing concern to make palliative care more culturally sensitive and contextually appropriate. This concern is also relevant in Indonesia, where the progress of palliative care, particularly in home-based care, has been slow. Like elsewhere in the world, there has been a growing awareness of the importance of shifting from a curative orientation towards a palliative one, especially in cases where further medical treatment is futile. In this paper we argue that the development of palliative care practices would benefit greatly from learning about the values that are important for patients, families, and health professionals. It is important to understand these values to support forms of care that aim to enhance quality of life. To demonstrate this, we analyse the care values people in rural Java evoke in their home palliative care practices. Methods We conducted an eight-month ethnographic study involving forty-nine patients, families, and health professionals. Results We identified three specific Javanese Islamic values: making an effort (ikhtiar), being sincere (ikhlas), and being in a state of surrender (pasrah). These values influenced the participants' activities in a palliative care setting. Based on our findings, we suggest three strategies to incorporate these values into palliative care practices and to better facilitate palliative care's integration into Javanese Muslim communities. The first strategy is to include efforts to reduce suffering and improve the quality of life using the concept of ikhtiar. The second strategy is to foster sincerity (ikhlas) to help patients and families accept the realities of their condition and provide care for patients at home. The last strategy is to clarify that palliative care is not synonymous with 'giving up' but can be seen as an act of pious surrender. Conclusions Our study identified three Islamic-Javanese values that can be incorporated to strategies aiming at enhancing palliative care practices, resulting in care focused on improving quality of life rather than futile attempts at a cure.</p>
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