

Are We Really Speeding Up Death? Exploratory Insights about Hospice Care from the American Muslim Community



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Background

- End-of-life care, particularly hospice, aims to enhance quality of life and provide comfort in final stages.
- Despite its benefits, hospice care is often misunderstood and underutilized, particularly by specific cultural and religious communities.
- Little is known about how Muslims in the United States perceive and engage with hospice care.

Objective

- To explore Muslim patients' and caregivers' perceptions and experiences regarding hospice care within the United States.

Methods

- **Study Design:** A Qualitative descriptive approach; semi-structured interviews with 11 Muslim participants.
- **Recruitment:** Through the Muslim Community Health Center and Community Advisory Board.
- **Data Analysis:** A Framework approach, using NVivo for coding, thematic analysis to identify core themes.

Results

Theme 1: Notions of When Hospice Care Should Be Sought

Participants had differing views on when hospice care should be sought, with many associating it with the final hours or days of life. This misconception often delayed the acceptance of hospice services.

"We're told that in hospice care, they give medicines so that you're not in pain, and you just lie down in bed until your last breath." – Participant 5

Theme 2: Islamic Ethical Concerns Surrounding Using Medications That May Cause Sedation and the Cessation of Feeding

Concerns About Sedation: Participants worried that medications like morphine could cause sedation, interfering with the ability to perform religious duties, such as the final testimony of faith (shahadah).

"You want to be in sense when you're leaving the world, just to say your shahadah when you're dying." – Participant 2

Dilemma Over Cessation of Feeding: Ethical concerns arose around stopping feeding for terminally ill patients, as families grappled with aligning this practice with Islamic bioethical values that emphasize preserving life while avoiding harm.

"The hardest was with her feeding... Family members insisted, 'You have to feed her,' but we couldn't force-feed her." – Participant 11

Theme 3: Families Who Used Hospice Care Reported Having Positive Experiences with Hospice Care

Cultural Sensitivity Matters: Families who used hospice care reported positive experiences when their religious beliefs were respected

"We always had Quran playing in the background... Faith was a central part of this process." – Participant 11

- **Comfort with Care Providers:** Positive experiences were highlighted when hospice staff demonstrated respect for religious preferences, such as providing gender-appropriate care provider.

"They respected everything we wanted... There was never a conflict." – Participant 7

Discussion

- **Impact of Misconceptions:** Skepticism toward hospice may prevent timely enrollment, denying patients the comfort and support it provides.
- **Ethical Balancing:** Tension exists between providing pain relief and maintaining religious obligations, particularly for medications affecting consciousness.
- **Cultural Sensitivity in Hospice:** Highlighting the need for culturally tailored education for Muslim patients and families.

Recommendations

- Raise awareness about hospice benefits and counteract misconceptions within the Muslim community.
- Include Islamic values in hospice protocols to support spiritual practices.
- Future research should identify knowledge gaps, address community concerns, and develop tailored interventions in hospice care.

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