

ABSTRACT

- Early integration of palliative care after a cancer diagnosis improves outcomes, yet few Latinx individuals access palliative care services. We conducted a participatory action study with Latinx community leaders to explore sociocultural perspectives on cancer and death that included conversations about end-of-life (EoL) care.

SIGNIFICANCE

- The leading cause of death for Latinx persons in the US is cancer (ACS, 2018).
- Some Latinx sub-groups experience health disparities in palliative and EoL care.
- Latinx community navigators successfully increased use of advance directives and hospice services (Fischer et al., 2018).
- Latinx persons prefer conversations about advance care planning (ACP) with family & clinician (Shen et al., 2019).
- The **purpose of this study** was to understand the meaning of cancer and death from the perspectives of Latinx community leaders framed in a palliative care training program.

METHODS

- **Study design:** Participatory Action Research guided by the Ethnocultural Gerontological Nursing (ECGN) model.
- **Research team:** 4 RNs, anthropologist, Latinx community leader, statistician, and 2 Honors students
- **Sample & setting:** 15 Latinx community leaders from 3 rural counties completed a palliative care training program.
- **Data Collection:** Three Focus Group Discussions (FGD) were held prior to the training program
- **Data analyses:** Key Words in Context (KWIC) and constant comparison techniques led to thematic findings

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FINDINGS

Overarching Context: Four Kinds of Hard

Themes 1 and 2 captured macro-level (sociopolitical) factors and Themes 3 and 4 captured micro-level (personal) factors

Theme 1: Receiving an Eviction Notice

“...cancer is like an eviction notice; you’re moving somewhere else.”

Theme 2: Getting in the Good Book

“God would have a big Book...you would have all your life until then [death] to make sure you were in the right Book.”

Theme 3: Talking is (Sometimes) Taboo

“I do not want to think that one of...my family has that [cancer]... I do not want to even name it in relation to my loved ones.”

Theme 4: Seeing Their Pain Makes Us Suffer

“...pain within themselves knowing that they have this um diagnosis and also pain for the family watching their loved one suffer...”



DISCUSSION

- Sociopolitical factors limit palliative care options for Latinx families with cancer.
- Trained Latinx palliative care advisors can fill service gaps
- Attitudes related to death occurred within a religious framework
- Prayer and visitation were important community-based strategies for symptom management
- Preparation for EOL and ACP decision-making can be integrated with traditional funeral planning
- Strategies that facilitate conversations about ACP included: advocacy, communication in the preferred language, and sharing low literacy health information

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