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 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 completed a palliative care training program in rural eastern NC.
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 analysis

ACKNOWLEDGEMENT

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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...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 measures for symptom management
The preparation for EOL can incorporate ACP decision-making with 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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