The Experience of Undocumented Individuals Denied Stem Cell Transplant for Hematologic Malignancies

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ABSTRACT

BACKGROUND: Undocumented individuals with hematologic malignancies in the United States face barriers to receiving often-curative stem cell transplant (SCT), instead receiving inferior treatment with higher mortality. Federal and state policies' impact on undocumented individuals' lived experiences goes unnoticed.

OBJECTIVE: To understand the experiences of this rare population of undocumented individuals with hematologic malignancies who cannot receive medically indicated SCT.

DESIGN, PARTICIPANTS, AND APPROACH: This qualitative study used semi-structured interviews with undocumented individuals diagnosed with SCT-eligible hematologic malignancies between June 2021 and June 2022 at an academic and a safety-net hospital in Colorado. Interviews were recorded, transcribed, and analyzed using principles of grounded theory and thematic analysis.

KEY RESULTS: Seven individuals (2 (29%) female, 5 (71%) male, mean age [SD] 44 [15.8]) were interviewed. Themes were divided into those unique to the undocumented immigrant experience and those unifying with the cancer illness experience.

Themes unique to the immigrant experience

Theme 1: Cancer and immigration status

- ° Debilitating cancer symptoms disrupt legal immigra- tion process
- ° Feeling dehumanized when health insurance deter- mines ability to live
- ° Fatalism and resignation to inadequate care

Theme 2: Appreciation and Gratitude for Advocacy

Awareness of physician advocacy

Theme 3: Pride and purpose in the United States

- ° Desire to make a positive impact on society
- ° Pride in immigrants' contribution to US workforce

Unifying themes related to cancer experience were

Theme 4: Adversity related to cancer care and treatment

- ° Feeling dismissed and delayed diagnosis
- ° Financial hardships intensify emotional and physical burden
- ° Burdening family
- ° Social isolation

Theme 5: Support and coping mechanisms

- Embracing positivity
- ° Religion as a source of comfort
- ° Critical support from family and friends
- ° Gratitude for compassionate care
- ° Appreciation for care that is unavailable in home country

CONCLUSIONS: This unique population faces intersectional challenges due to immigration status, insurance access, and cancer. The experiences of undocumented individuals highlight the need for state policymakers to expand coverage for comprehensive cancer care.