TRUST AS A CENTRAL FACTOR IN HOSPICE ENROLLMENT DISPARITIES AMONG DIVERSE PATIENTS: A QUALITATIVE STUDY OF INTERRELATED BARRIERS IMPACTING TRUST

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Introduction

- Disparities in end-of-life (EOL) care remain among ethnic/racial minority populations.
- Choosing hospice care depends on goals of care (GOC) discussions founded on trust.
- While studies examine barriers to hospice, few explicitly examine the role of trust.
- This study explores factors contributing to disparities in hospice enrollment and how these impact trust.

Methods

- **Design**: Qualitative, individual interview study.
- **Participants**: Multiple stakeholders in EOL care.
- **Data Collection**: In-depth interviews, audio-recorded and transcribed as part of a broader study of hospice enrollment in diverse patients.
- **Analysis**: Three researchers did a secondary data analysis, using grounded theory, focusing on trust as the core phenomenon. They independently analyzed transcripts, then held iterative group analysis meetings until they reached consensus regarding themes, subthemes, and relationships.

Table 1: Themes and Subthemes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
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<tbody>
<tr>
<td>Trust</td>
<td>Trust on a Personal Level, Trust on a Systems Level, Central to GOC discussions &amp; decision making</td>
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<tr>
<td>Fear</td>
<td>Of Death, Loss, &quot;Giving Up&quot;, Words (cancer, morphine, hospice), Fears of patient/family, Fears of physicians</td>
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<tr>
<td>Relationships/ Communication</td>
<td>Between physician and patient/family, Within healthcare team, Within families</td>
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<tr>
<td>Lack of Knowledge re: Hospice &amp; Palliative Care</td>
<td>Patient, Community, Physicians</td>
</tr>
<tr>
<td>Religious/Spiritual Beliefs</td>
<td>Accessibility of interpreters, Need for interpreters comfortable with EOL, Burden on family members, Interplay between culture &amp; language</td>
</tr>
<tr>
<td>Cultural Beliefs and Experiences</td>
<td>Historical disparities/mistrust of healthcare system, Prior personal/family experiences, Cultural views of physician (extreme trust to extreme mistrust), Beliefs re: EOL Care, Eurocentric healthcare approach (disconcordance or concordance), Variation in importance of family involvement, Variations between and within &quot;cultures&quot;</td>
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Results

- Trust as a central factor in hospice enrollment disparities among diverse patients.
- Multiple stakeholders in EOL care have varying levels of trust, impacting enrollment decisions.

Figure 1: Relationship Between Themes

Representative Quotes

- "When I talk about hospice, I always ask, ‘what do you know about hospice?’ … Because I’ll either get, ‘oh, it’s wonderful, my father died on hospice, they took good care of him,’ … Or I’ll get, ‘well that’s where they hook you up to an IV and kill you, right?’"

- "Many cultures are very, very, very leery about the American people, because the American people either give you too much medicine and then put you in a nursing home, and that’s not something most cultures believe in. And so we have to gain their trust."

Conclusions

Minority patients experience multiple factors that negatively impact trust, which in turn affects provision of high quality EOL care. More research is needed.

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References

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