Korean Americans’ Preferences for and Barriers to End-of-Life Care Planning and Use of Palliative Care Services

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BACKGROUND

- Race/ethnicity as predictors for different preferences for end-of-life care options (George, 2002).

- Unclear on what specific aspects of culture influence end-of-life decision making.

- Underrepresentation of ethnic/racial groups in hospices. e.g., Asians less likely to use hospice than Whites (Ngo-Metzger et al., 2003).

- Very few studies examining racial/ethnic barriers to utilizing hospice and advance care planning.
STUDY AIMS

1. To examine Korean American elders and adult family members’ views on end-of-life care and planning by identifying:
   1. Knowledge and preferences for advance directives and hospice care;
   2. The role of family in decision making;
   3. Any barriers to utilizing advance directives and hospice care;
   4. Solutions to reducing identified barriers.

2. To develop and disseminate Korean language educational instruments regarding end-of-life care options and planning.
1. **Design:**
   • Qualitative study using focus group method conducted in Korean language.

2. **Sample:**
   • Korean American residents from two counties on the Gulf Coast of Florida.
   • The Elder focus group: Elders who were aged 60 and older residing in two counties.
   • The Adult Child focus group: Adult children who were aged 18 and older and were likely to provide care for an elderly family member in one of the two counties.

3. **Measures**
   • **Interview guide:** A semi-structured interview guide developed and evaluated for content validity by one expert in end-of-life care and planning.
4. **Data**
   - Focused group interviews were audio taped and transcribed verbatim in Korean.
   - Transcripts were reviewed along with taped audio recordings to verify accuracy in Korean, and then, were translated into English.

5. **Analysis:**
   - Modified grounded theory (Strauss and Corbin, 1990).
   - Steps
     - Theme categories were generated based on a set of research questions.
     - Data related to the research questions were placed under the theme categories.
     - Themes were identified by content analysis.
     - Identified themes were compared between groups and similarities and differences were noted.
### Table 1.

**Participant Characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Elders (N=20)</th>
<th>Adult Children (N=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>16 (80%)</td>
<td>5 (30%)</td>
</tr>
<tr>
<td><strong>Age (Mean)</strong></td>
<td>68</td>
<td>40</td>
</tr>
<tr>
<td><strong>Age of parent(s) (Mean)</strong></td>
<td>N/A</td>
<td>74</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed high school</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Some college</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Completed college</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td><strong>Years in the U.S. (mean)</strong></td>
<td>29</td>
<td>13</td>
</tr>
</tbody>
</table>
FINDINGS

1. Cultural barriers

2. Institutional barriers

3. Solutions to reducing these barriers
Cultural Barriers

Unpredictable nature of life

“I would still try curative treatment even if the doctors confirmed that there was no hope of recovery because you just don’t know about this kind of things.” (Elder)

Filial piety ‘효’

“They will do anything they could even though I don’t want unnecessary treatments personally.” (Elder)
Cultural Barriers

Family as the final decision maker.

“Family will make the decision on my end-of-life care. Even if I had completed an advance directive and left it with my children, they will be the one who will make the decision through family discussion.” (Elder)

Discomfort in end-of-life communication.

“You don’t talk about it explicitly with your parents because in Korean culture, people think that if you talk about negative things like death, such things will actually happen.” (Caregiver)
Participants from both groups had **no** knowledge of or had **misconception** about advance directives and hospice.

“I think advance directive is a will which provides instruction on how to distribute wealth.” (Elder)

“I’m not the hospice a program provided by the government like a nursing home.” (Caregiver)
Participants from both groups expressed concern regarding signing a legal document on medical care.

“I think there is a sense of anxiety about signing a legal document in the fear of not being able to reverse the decision on one’s own life. In other words, what if I wanted to live even on life support but I couldn’t because I had chosen not to use life support in the living will.” (Caregiver)
A wide range of preferences for end-of-life care including preferences for palliative and comfort only care.

“I think that if my parent were terminally ill, I would prefer the comfort care, which would be hospice. I want my parent to feel comfortable, rather than inflicting too much pain in an effort to try some kind of medical experiment on him.” (Caregiver)
Cultural norm of home death.

“According to the Korean tradition, it is encouraged to avoid dying in a place other than one’s own home. This tradition could be a positive aspect of hospice that could have a special appeal to Koreans.” (Caregiver)
Value of advance directives as a guiding tool for making end-of-life decisions.

“*I think the form will be a useful tool for children to use in making the decision. At least they will know what my preferences would have been.*” (Elder)

“I personally prefer my parents to have it because it would make our job much easier. “ (Caregiver)
Common sources of health/social information included: Korean American organizations, churches, local newspaper, and physicians.

Expressed desire and need for educational seminar or individual counseling on various health issues including end-of-life care.
DISCUSSION

This study supported previous research (Blackhall et al., 1995; 1999): family-centered, shared decision making by Korean American families.

We also found:

– A wide range of preferences for and attitudes toward advance directives and hospices among elders and caregivers.
– Both cultural and institutional barriers to use of hospice and advance directives.
– Solutions to address and reduce these barriers.
DISCUSSION

• Institutional barriers can be reduced by providing education opportunities.

• Advance directives may serve as useful tools that allow elder’s wishes (including desire to know) to be known to the family when engaged in end-of-life decision-making process.

• As a part of this study, information on advance directives and hospice in Korean was developed based on feedback from participants on the tools.
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REFERENCES


