**What Is Palliative Care and Do I Need It?**

**Preliminary Findings from a Survey in an Asian Community in USA**

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### Significance

- Although Asian Americans are one of the fastest growing ethnic groups in the U.S., the rates of palliative care use at end of life (hospice care) are low.
- To date, the limited research that has been conducted suggests that due to lack of knowledge of hospice and advance care planning, Asians are less likely to access palliative care and consistently report receiving poorer quality palliative care.
- The purpose of this study was to examine overall level of knowledge of palliative care and advanced care planning among Asian populations, potential variations in the knowledge among subgroups within the Asian populations, as well as to identify factors associated with those variations.

### Methodology

- **Data**: Data collection was conducted at public events and focus group meetings in the Southwestern region of the U.S., between October 2018 to February 2019. A total of 212 surveys were collected; 154 surveys were included in the data analysis.
- **Survey Instruments**: Five instruments were used in this study: a demographic survey created by the researchers, the Knowledge of Care Options Instrument (KOCO), the Palliative Care Knowledge Scale (PaCKS); the Hospice / Palliative Care Questionnaire; and the Advance Care Planning Questionnaire.
- **Analyses**: Descriptive analyses were conducted on individual questions in the survey. Six dependent variables derived from the survey instruments were analyzed using multivariable models to examine potential associated factors. The key independent variables being used in the multivariable analyses were specific ethnic groups within Asian population (Chinese, Korean, and Vietnamese, Filipino and other Asians). Filipino was taken as reference group. Other variables being analyzed included age group (< 30, 30 – 44, 45 – 59, >= 60), sex, marital status, education level, religion, having a chronic condition(s), and self-rated health status.

### Results

- Among the survey participants, 14.3% were Vietnamese, 25.3% were Koreans, 26.0% were Chinese, 28.6% were Filipinos; 95.9% were females, and the average age was 49.4 years old. More than half (59.7%) of the participants earned a bachelor or higher degree; 19.5% received high school or lower education; 39.0% were Catholic, 19.5% were Christian, 19.5% were Buddhist and 12.3% were without religion affiliation. About 86% immigrated to the US and over 70% rated their health being good.
- Less than half of the participants in this study reported having heard of palliative care (46.1%) and advanced care planning (40.3%).
- For KOCO score, the unadjusted average score of all participants was 6.03 with Chinese having the highest average of 6.65 and Vietnamese having the lowest average of 5.55.
- For PaCKS instrument, group average ranged from 3.50 (Vietnamese) to 4.72 (Korean).
- In the area of “heard of PC”, as compared with Filipinos, both Chinese (0.19 [0.05, 0.73]) and Vietnamese (0.22 [0.06, 0.48]) were less likely to have heard of palliative care whereas Korean showed a similar likelihood (0.98 [0.36, 2.71]).
- In the area of ACP, no difference in “ever heard of advanced care planning” was observed among the four Asian groups.
- Age group was negatively associated with awareness of PC and ACP, meaning older people may be less aware of PC and ACP. Age group was also negatively associated with KOKO and PaCKS scores.
- Having higher education level, no religion affiliation, and Buddhism were positively associated with “heard palliative care before” while for “heard of ACP”, only education level was positively associated with it (1.60 [0.93, 2.84]).
- For “like to receive more information about PC”, Koreans tended to say Yes more often than Filipinos (OR [CI], 4.60 [1.34, 15.81]) while Chinese and Vietnamese were similar to Filipinos.
- When the health status moved up one level higher, the odds of “willing to endure specific life-prolonging intervention” increased by 74% (OR [CI], 1.74 [1.07, 2.82]).
- Finally, no difference in selecting a family member(s) as the first preference of power attorney was found across the four Asian groups.

### Factors Associated with Palliative Care Awareness & Knowledge

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio</th>
<th>95% C.I.</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>KOCO</strong></td>
<td>1.00</td>
<td>-</td>
<td>-</td>
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<tr>
<td><strong>PaCKS</strong></td>
<td>1.00</td>
<td>-</td>
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### Discussion

- This low level of awareness indicates that Asian respondents are underexposed to these services and implies that there is room for improvement in message framing and message dissemination strategies in palliative care and advance care planning promotional programs to increase the level of awareness among Asian target audiences.
- Wide variation in awareness and knowledge among Asian subgroups. Hence, education material should be tailored depending on priority target for education, Vietnamese, increase knowledge about PC (Filipinos), increasing awareness (Chinese) or disseminating more information on PC & ACP (Korean).
- Factors for this low level of awareness and knowledge about PC and ACP among older Asians in this study requires further investigation.
- 85.8% were immigrants from their original countries to the U.S., and may keep their original cultural norms about death which may lead to the reluctance to have conversations about end-of-life. This implies that tailored educational materials should be developed for older age groups in immigrant Asian communities.
- Culturally sensitive education may promote better understanding of EoL issues and serve as a critical enabler toward ACP awareness, which in turn can increase confidence and ability to engage in completing AD.

### Limitations

- This study used a cross sectional design and involved a regionally defined sample and limited sample size. Therefore, caution should be used when drawing causal inferences.

### Conclusions

- The present study contributes to the literature by adding a perspective that reveals a low level of PC awareness and knowledge for a diverse Asian group and highlights differences among the Asian nationalities.
- The low levels of PC awareness and knowledge in the present study raise concerns and shed light on the critical need for culturally appropriate education programs.
- More diversity in the healthcare workforce and healthcare education should be prioritized to undeserved linguistically minor groups to achieve better communication among their cultures.

### References

- Johnson, K.S.Racial and ethnic disparities in palliative care. Journal of Palliative Medicine,2013; 16 (11), 1239-1334

### Acknowledgements

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