“Unless You Bring It Up, You Won’t Know the Reactions of the People”: Older Japanese Americans’ Perceptions Toward Hospice Care and Advance Care Discussion and Planning

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Dear Editor:

It is well known that Asians and Pacific Islanders utilize hospice at very low rates (3.1%) compared with whites and other minority groups¹ despite being the fastest growing racial group in the United States between 2000 and 2010.² Research on Japanese Americans’ attitudes toward hospice, advance care planning, and end-of-life care discussion is limited and a greater understanding of their knowledge and attitudes is important for increasing access to and utilization of end-of-life care. Therefore, the purpose of this study was to explore Japanese Americans’ knowledge of and attitudes toward hospice care, advance care planning, communicating preferences, and developing advance directives.

Two qualitative focus groups were conducted (one each in English and Japanese) among community-dwelling Japanese American adults aged 65 years or more. Participants were from a social service agency serving Japanese older adults in a large metropolitan city ($n = 20$). Focus groups were guided by an open-ended research protocol.

Predominant themes were (1) misconceptions/misinformation about hospice, (2) attitudes toward hospice and end-of-life care, and (3) cultural characteristics and traditions at end of life (Table 1). Findings indicate not only a need to increase hospice education among Japanese Americans but also suggest an interest in and acceptance of this type of information. Relatedly, participants affirmed a cultural shift among the current generation of older Japanese Americans as open and willing to discussing end-of-life care whereby previous generations were not. Cultural considerations included not wanting to be a burden, preference for family/group decision making, and mixed preferences around disclosure of prognosis.

Results suggest one reason Japanese Americans utilize hospice at low rates may be lack of knowledge and misconceptions about hospice and end-of-life care in the

United States, creating a barrier to informed decision making when navigating care options. However, our results also identified pervasive interest in learning about hospice and openness to information, highlighting an opportunity for education.

Despite cultural stereotypes held, many older Japanese Americans in our focus groups appeared willing to engage in prognostic and advance care planning conversations, particularly when accompanied by diagnoses of serious illness. Yet despite recognized cultural shifts in conversations, traditional values persist in the inclusion of family members in care discussions and decisions, and concern about limiting burden to family members and caregivers. This finding directly opposed results in a study of Chinese Americans that suggested hospice care may be perceived as bringing a greater burden to family members.³ Nevertheless, hospice care may serve as a culturally parallel response to relieving family burden among Japanese Americans.

Finally, results of this study and two others point to an attitudinal shift toward greater acceptance of hospice and Western values among Japanese Americans.⁴ Although some researchers have attributed this shift to acculturation level, others have found age cohort (>70 years) to be associated with generational values. Regardless of the reason, these results underline the importance of acknowledging within-group differences and caution against stereotyping, resulting in assumptions about what people within an ethnic or cultural group think or how they will behave. This is especially important for healthcare providers caring for older adults and those with serious illness.

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TABLE 1. PERCEPTIONS OF HOSPICE, ADVANCE CARE PLANNING, AND COMMUNICATING PREFERENCES

Theme 1: Misconceptions/misinformation	
Subtheme 1. Inaccuracies	
116	"Is it something new?"
113	"Didn't it originate primarily when we had the outbreak of AIDS?"
103	"When I heard the word 'hospice,' I thought it had something to do with the hospital, but I'm surprised you can do it at home. People will like it and be interested."
Subtheme 2. Answer-seeking dialogue	
108	"The doctors usually tell you, right? Since I would not know whether I need hospice or not."
103	"Home care is the same as hospice, right? I think many people make an assumption that hospice equals hospital when it's not, apparently...So home treatment is called hospice, too, right?"
Subtheme 3. Eligibility concerns/questions	
108	"In order to be a part of the program you need to pay, right? So there are many people out there who would like to be part of hospice but can't due to financial reasons, correct?"
117	"So for hospice you need to have someone to take care of you, right? You need a caregiver? I mean...if you don't have anybody, you can't have it?"
Subtheme 4. Education	
102	"...And one should not be too picky regarding the name 'hospice.' I think the best thing is to announce about the hospice program since many people are unaware about the program. I think they should be more aware of hospice while they are in good shape, while one is healthy."
109	"I want a meeting like this again. Maybe with a guest speaker next time of those who have experienced hospice program."
Theme 2. Attitudinal shift	
Subtheme 1. Hospice care	
107	"[a hospice recipient is] Someone who is being neglected by a doctor."
112	"[a hospice recipient is] Someone who is waiting for their death since the doctor cannot do anything."
108	"I think it is a privilege to being able to have that kind of care...I think you are very lucky if you are in hospice."
Subtheme 2. Generational changes	
106	"I think hospice itself is viewed completely differently right now compared to the old days."
101	"Things have changed throughout the years. I know people who actually come from Japan to receive hospice care here. Since in the life in Japan, once a certain thing is accepted, people will open up to it. However, if it is not [accepted], it is very difficult to pursue something like this. For instance, if it were 10 years ago, and if you live in Japan, it would be difficult and most people would not want to be in hospice. And people probably would not want to be even known that they are in it. Japanese people have different perspectives but it has changed throughout the years but it is still a touchy subject to talk about."
103	"It depends on your age. In our generation we do not mind talking about death. For instance, I'm completely fine talking about death, however, for some people it is difficult due to religious beliefs."
Theme 3: Cultural characteristics	
Subtheme 1. End-of-life communication preferences with family and clinicians	
115	"...But the doctors [are] just there to keep up my health so we don't discuss about when I die."
119	"Especially for tube feeding, and you don't want that. It's best to tell the family and the doctors, and doctors need to know your wishes and what kind of treatment you would prefer."
117	"You need to let your wishes out there to the doctor or the hospital...[but] sometimes you need to change your doctor due to insurance but you may have to change physicians due to transfers. That's why people don't want to tell that information [end-of-life wishes]."
Subtheme 2. Timing of advance care planning	
105	"No, I think I have enough time to even start talking about that...I do not think it's necessary since I have more time."
107	"I think it depends on your health status. If you are very ill and that subject is brought, and the subject is brought while you are still in good condition completely changes things."
114	"More or less, I have finalized a lot of things so that I know after 80, you go downhill. So anything can happen anytime."
Subtheme 3. Shift in disclosure of terminal prognosis	
102	"Since in Japan, many people tend to commit suicide when those topics arise, physicians in Japan refuse to talk about those things to patients. Usually they ask the family members to bring it up and the family members make that decision...so usually a family member tells the patient instead of the doctor."
108	"I would like for the doctor to tell me as soon as possible [terminal prognosis of six-months or less]."
102	"...Definitely it differs based on the person's personality. I mean, one might be fine to hear it bluntly and some may not like that. But unless you bring it up, you wouldn't know the reactions of the people. One should be able to talk about hospice in their daily conversations without avoiding the subject."
Subtheme 4. Desire to not burden family but live at home	
107	"[I would elect hospice because its]...More of a courtesy for those who are left behind."
101	"A family oriented approach is such a great system. I was very impressed."
113	"I think the big plus about hospice is the fact that they can do it [at] home. Since the majority of people want to be at home with familiar surroundings, family...I know when my parents passed away if they had a choice at that time, they would like that and we didn't even think about hospice."

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