

Discussing End-of-Life Care Preferences With Family: Role of Race and Ethnicity

BACKGROUND

As people age and become more vulnerable to chronic, age-related diseases, it becomes increasingly important that they communicate with family concerning the care they would wish to receive if they were seriously ill but not able to speak for themselves. However, despite the growing awareness of the importance of these conversations, many older adults have not had them. This trend is even more prominent among minorities, with some research suggesting that only about 50% of these groups engage in end-of-life (EOL) discussions with their loved ones. This might be occurring due to religiosity or the construct of familism, as these have been found to influence decision-making among minority older adults. Therefore, this study's purpose was to examine whether demographic characteristics, such as race and ethnicity, played a role in the prevalence of EOL care discussions with family.

STUDY METHOD

Measures. A one-time survey was used to examine EOL care preferences and other variables among adults 50 and older. A total of 364 English- or Spanish-speaking participants were recruited from six locations (i.e., senior centers, senior service organizations, or housing complexes) in five Florida counties. The primary variable assessed was whether EOL care preferences had been discussed previously with family members.

Other variables included financial stability, health conditions and number of chronic ailments, as well

as family involvement in health care decision-making, support in decision-making, health literacy, and religiosity. These variables were chosen based on prior research concerning whether older adults engaged in EOL discussions with family members.

Analytic method. First, bivariate analyses were conducted to determine if there was a relationship between each variable and whether an EOL discussion had occurred. These included a three-group race and ethnicity variable (non-Hispanic White, African American, and Hispanic). A separate analysis was conducted to determine whether there was a significant relationship between any of the three groups and having had an EOL care discussion. In the analyses that followed, a multivariable logistic regression was used to examine the likelihood of participants of each racial and ethnic group having engaged in EOL discussions with family members, controlling for the variables that were significant in the previous analyses.

FINDINGS

The results of this study found that 69% of all the participants had discussed their EOL wishes with their family. Considering differences by race and ethnicity, 73% of the White participants, 68% of the African American participants, and 50% of the Hispanic participants had engaged in such discussions. For White and for African American participants, no significant relationship was found between their race and whether they had or had

not engaged in EOL care discussions with family members. However, compared to non-Hispanic Whites in the sample, Hispanic participants were significantly less likely to have had these conversations. Further analyses showed that this relationship was moderated by how much these individuals involved family or friends in their general healthcare decision-making, such that those with lower levels of family involvement in general healthcare decision-making were also less likely to have discussed EOL care wishes with family.

Analyses also found that participants who were married were less likely to engage in EOL discussions with their family. Additionally, participants were more likely to engage in EOL discussions if they had multiple chronic health conditions, had higher levels of support in decision-making, and had previously discussed EOL with their healthcare providers.

POLICY IMPLICATIONS

This study reported that Hispanics were less likely than non-Hispanics to engage in EOL care discussions with family, and that this was largely moderated by family/friend health-care involvement. In other words, for Hispanics more than for others, the extent to which they involved family in their general healthcare decisions appeared to influence whether they talked to family members about their EOL care wishes. This suggests that EOL discussions may not be singular acts but are part of larger, possibly ongoing discussions involving family and doctors. It was

also found that for all races and ethnicities in the sample, those who discussed EOL care wishes with their doctor were more likely to have discussed this with their family. Overall, the study suggests that doctors may be able to encourage older adults to discuss their EOL care wishes with family by incorporating discussions of EOL care into more routine, ongoing health care discussions. In addition to this study, others have reached similar conclusions concerning the role of family in healthcare decision-making. Policy makers should take into consideration better educating family and friends on the importance of their involvement in the general healthcare decision-making of their loved ones. This could promote the growth of EOL discussions within communities and better prepare family members as their loved one's age.

Original Article

Peterson, L., Hyer, K., Meng, H., Dobbs, D., Gamaldo, A., & O'Neil, K. (2019). Discussing end-of-life care preferences with family: Role of race and ethnicity. *Research on Aging, 41*(9), 823–844. <https://doi.org/10.1177/0164027519858716>

This policy brief was written by T. Vivas, H. Rouse, and L. Peterson of the University of South Florida, School of Aging Studies and Florida Policy Exchange Center on Aging.

For further information contact author L. Peterson via email at ljpeterson@usf.edu