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End-of-life wishes vary among racial and ethnic groups, and between genders, study finds

## Study explores views of Arab Americans, Hispanics, blacks and whites

Many Arab Americans would prefer not to go to a nursing home as they near the end of their lives, while many African Americans are comfortable with nursing homes and hospitals. Many Hispanic people are strongly concerned about dying with dignity. And many white people don't want their families to take care of them, but they – like members of other racial and ethnic groups – want their families nearby as they live out their last days.

Those are some of the findings of a study of 73 focus group participants who were asked numerous questions about end-of-life care. The study, in the current issue of the Journal of the American Geriatrics Society, found sometimes divergent views in how the different groups view health care, spirituality, family, and dying.

"One of the most important findings in our study is that there are so many different points of view, it is important for health care providers to treat everyone as an individual," says lead author Sonia A. Duffy, Ph.D., R.N., research investigator with the Center for Practice Management and Outcomes Research at the Veterans Affairs Ann Arbor Healthcare System, and with the departments of Otolaryngology and Psychiatry at the University of Michigan Medical School.

"We should keep in mind that our country's medical system is based on Western values, and that those values may not translate to other cultures," Duffy says. "Deeply rooted cultural beliefs and values are difficult to influence."

The study also found differences between the points of view of the genders within the various groups. For example, Hispanic men in the study, in general, wanted little medical intervention at the end of life, while Hispanic women in the study tended to

favor extensive medical intervention. The split was similar between African American men and women.

More than other groups, Hispanic men in the study said they prefer assisted suicide in some instances and would like to rename assisted suicide "assisted dying." One of the Hispanic men in the study said, "I don't think it is suicide if you've already been predetermined and everyone knows that you're going to die." Expressing an opposing view, one of the black women in a focus group said in opposition to assisted suicide, "Anything might turn around."

The 10 focus groups included people who identified themselves as Arab Muslim, Arab Christian, Hispanic, black, or white. They were all 50 years and older. They participated in exercises, scenarios and discussions about end-of-life issues, and they completed questionnaires that, among other things, helped measure how closely they were connected with their cultural group.

## Among the findings:

All Arab participants indicated that the family takes care of someone who is dying, and many noted that the whole neighborhood is involved when someone is dying. Arabs "try desperately not to go in a nursing home," the study says. Many of the Arabs in the study also indicated that they do not want heroic measures taken to prolong someone's life. They tended to be against telling their family members bad news, but they wanted to know the news themselves. Compared with others in the study, those of Arab descent "were significantly more concerned with their accomplishments in life and preferred to have their finances in order before dying." By and large, they were not aware of hospice care.

"Dying with 'dignity and care' and 'not having to suffer or someone having to change your diapers' [were] of greatest concern to Hispanics," the study notes. They were receptive to hospice care and hospitals, but said it was important to avoid going to a nursing home. They were more likely than other groups to want to control their place of death, not to want a feeding tube and not to have do-not-resuscitate orders. They also were the only group to mention they are in favor of alternative medicine.

During the focus groups, black men did not feel strongly about the importance of having family and friends take care of them, and they said they did not want to burden their loved ones. Indeed, black people in the study would prefer staying in an intensive care

unit or nursing home, or to have hospice care, rather than being at home under the care of family. Many black men expressed distrust of doctors without even being asked about the subject, and some expressed concern related to past medical-related injustices experienced by black men.

Whites in the study indicated that they did not think it was the family's responsibility to take care of them. They were open to hospice care, hospitals and nursing homes, but generally preferred to die at home. It was important for them to have choices and an advance directive, and many were opposed to extensive measures to extend life. More so than the other groups, whites in the study were likely to want to know what to expect about pain and other effects of their conditions.

In addition to Duffy, authors of the study were Frances C. Jackson, Ph.D., R.N., from the School of Nursing at Oakland University in Rochester, Mich.; Stephanie M. Schim, Ph.D., R.N., from the College of Nursing at Wayne State University in Detroit; David L. Ronis, Ph.D., from the Center for Practice Management and Outcomes Research at the Veterans Affairs Ann Arbor Healthcare System and the School of Nursing at U-M; and Karen E. Fowler, M.P.H, from the Center for Practice Management and Outcomes Research at the Veterans Affairs Ann Arbor Healthcare System.

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## For more information:

- Booklet about death and dying:
  www.med.umich.edu/1libr/aha/umgrief.pdf
- Resources and information about end-of-life issues: www.nlm.nih.gov/medlineplus/endoflifeissues.html
- Talking about your final wishes: www.aarp.org/families/end\_life/a2003-12-02-endoflife-finalwishes.html