# An Experimental Survey of Surrogate Decision-Making for Older Adults with and Without Dementia

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More than two-thirds of older adults will require surrogate decision-makers for healthcare near the end-of-life because of cognitive and/or physical impairment. While written advance directives are often recommended as a way to ensure receipt of preference-concordant care, little is known about whether these documents actually influence treatment decisions. Currently, many patients receive aggressive, life-extending medical treatments that have little impact on their total length of life, are financially costly, and can reduce quality of life. We designed an experimental survey to provide an investigation into how surrogates make end-of-life decisions for patients with dementia. Our sample consisted of more than 6,000 US residents recruited online through the survey company Ipsos. The sample is nationally representative of the US population on sex, age, race and ethnicity and includes subsamples of caregivers of another adult, patients with chronic illness, and a random sample.

We asked respondents what decisions a surrogate should make in a series of scenarios. We employed a study design that cross-randomized characteristics of the patients' impairment (permanent cognitive impairment or physical impairment without cognitive difficulties),

characteristics of advance care planning, social norms and physician recommendations. Specifically, we asked respondents what decisions a surrogate should make in situations where we varied characteristics of the patient's impairment (whether they would be cognitively normal or demented and bedridden or not if treatment was successful) and characteristics of advance care planning (advance directive requesting all care possible, advance directive requesting comfort care only, advance directive that does not describe preferences for life-extending treatments, and no advance directive).

We found marked differences in surrogate's responses when there was an informative advance directive versus no advance directive or one that did not apply to the patient's situation. Surrogates chose life-extending treatment for 79.2% of patients who requested all care possible in their advance directive versus only 13.8% of those who wanted comfort care only. When there was no information about patient preferences, surrogates chose life-extending treatments 40% of the time. Surrogates were much more likely to select life-extending treatments for patients who were cognitively normal (65% versus 33.4%, $p < 0.001$), they were also more likely to select treatments that matched cognitively normal patients' previously expressed wishes than to select treatments previously requested by patients with dementia, including a 21.2 percentage point reduction in selecting life-extending treatments for dementia patients who had previously requested it through advance care planning. When there was no information available about the patient's preferences, surrogates were more likely to choose treatments that matched their own preferences. Physician recommendations were associated with 10 to 20 percentage point differences in treatment recommendations, while comments about social norms ("most patients in this hospital…") produced smaller differences.

Findings suggest that surrogate decision-makers follow written directives when directly applicable to the situation and concordant with their own preferences, and rely more heavily on their own preferences when there is uncertainty about the patient's wishes. Physician recommendations are also influential. Helping patients to designate surrogate decision-makers with similar treatment preferences may improve rates of preference-concordant end-of-life care. Even when patients prefer life-extending treatments, surrogates are less likely to choose them for dementia patients.