

## *Dementia, Goals of Care, and Personhood: a Study of Surrogate Decision Maker's Beliefs and Values*

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### **Background**

Patients with advanced dementia may have someone appointed to make medical decisions for them since they do not have the capacity to do so on their own—these individuals are called surrogate decision makers. The role surrogates play is sometimes very difficult and may place a burden on them as the dementia progresses. Communication between physicians and surrogates may help guide decision making by paying attention to the surrogates' beliefs, values, and intentions. This can be enhanced by making goals of care clear in conversations between physicians and surrogates.

### **Goals of the Study**

This study aimed to increase knowledge about surrogates' understanding and ability to describe goals of care, foundational beliefs (value as a human being, dignity, purpose in life, etc.) and ethical values (loved ones best interests, quality of life vs. prolongation of life) through closed-ended and open-ended questions.

### **Who was included in the study?**

Twenty surrogates were chosen to participate based on patient eligibility. They chose a surrogate decision maker if the physicians responsible for the patient confirmed the patient was unable to make his or her own medical decisions due to dementia. The surrogates' age ranged from 36-81 years with 60 being the average. Sixteen of the twenty participants had durable power of attorney—meaning they were explicitly appointed to make all healthcare decisions for the patient.

### **What did the study find?**

There were a variety of results, but some of them were:

- 15 of 20 surrogates believed their loved ones' dementia had affected their own mental or physical health
- The majority of surrogates believed that providing help for their loved one make them feel more useful and able to appreciate life more
- The majority of surrogates had spoken with their patients' physicians or nurses about treatment goals for their loved one
- The majority believed their loved ones' life still had a purpose and was a life worth living, despite their advanced dementia
- 19 of 20 said they were willing to authorize the use of intravenous fluids or antibiotics, while few were willing to authorize resuscitation (intensive life saving treatment) in case of a heart attack or a feeding tube if the patient stopped eating
- 9 of 20 were unsure about their willingness to authorize a feeding tube
- Few believed that dementia had significantly reduced their loved ones' value as a human being, dignity or other people's respect for him/her

## Conclusions

Discussing goals of care between physicians and patients' family members allows them to assess the value of potential treatments in relation to their goals. Little is known about how surrogates' convictions about personhood may affect the goals of care and treatments they are willing to authorize. Since 9 out of 20 were unsure if they would authorize a feeding tube, there may be a need for discussion concerning that topic. Often people with severe dementia stop eating and die as a result. Many people see this as a natural end to an illness that eventually leads to death from one cause or another. Others want to keep their loved one alive despite the reduced quality of life of a person with advanced dementia. A limitation of this study was this was a relatively small group of surrogates who were gathered from one Midwestern institution in a rural state with a lack of ethnic and racial diversity. More investigation needs to be done to determine if these results represent a larger, more diverse population.

*The summary above is based on a study by Lauris C. Kaldjian, MD, MPH, Laura A. Shinkunas, BA, Mercedes Bern-Klug, PhD, MSW, and Susan K. Schultz, MD. The full article appears in American Journal of Hospice & Palliative Medicine; 27(6) 387-397. This work was supported by a grant from the University of Iowa Social Sciences Funding Program. Dr. Schultz was supported by an Agency for Healthcare Research and Quality (AHRQ) Centers for Education and Research on Therapeutics cooperative agreement #5 U18 HSO16094 (the Iowa Older Adults CERT).*