

### **Effect of the Goals of Care Intervention for Advanced Dementia A Randomized Clinical Trial**

#### **Take Away Points**

- The goals of care (GOC) decision aid intervention is effective in improving end-of-life communication for nursing home residents with advanced dementia.
- Clinicians were more likely to address palliative care in treatment plans, use Medical Orders for Scope of Treatment (MOST), and less likely to send patients to the hospital.

#### **The Issue**

Over 5 million Americans have dementia and 67 percent of these patients die in nursing homes. Due to the loss of meaningful communication and functional dependency, family members have to make difficult choices on behalf of persons with dementia, but families report limited communication and support for common decisions such as resuscitation, tube feeding, and hospital transfer. Decision aids improve shared decision making by informing and framing health care choices to help patients and families prioritize goals to guide treatment.

However, few decision aids are designed for dementia. Therefore, the Goals of Care (GOC) intervention was developed to test if it improves quality of communication and decision-making, and improves palliative care for advanced dementia.

#### **Study Methods and Design**

The study was a single-blind cluster randomized trial including 22 nursing homes within a 60-minute driving radius of the University of North Carolina-Chapel Hill campus. Nursing home randomization was matched by profit vs. nonprofit status and percent African American residents. Residents were eligible if they were aged 65 years or older, had severe to advanced dementia (verified by nurse, 5-7 on the Global Deterioration Scale [GDS]), and had an English-speaking family decision maker. 302 resident-family dyads agreed to participate the study.

The intervention consists of an 18-minute GOC video decision aid and a structured meeting with the care team. The video provided information on dementia, goals of prolonging life, supporting function, or improving comfort, treatments consistent with each goal, and how to prioritize goals. Nursing home staff received one-hour training on structured discussion. Family decision makers in control sites were given an informational video on interacting with dementia patients and standard of care while the nursing home staff was given a 45-minute training session on study procedures.

Primary outcomes were compared at 3, 6, and 9 months (or death). The primary outcomes were 3 family-rated measures at 3 months: (1) Quality of Communication (QOC) scores for the nursing home, (2) concordance with clinicians on goals of care, and (3) the Advanced Care Planning Problem score. Secondary outcomes evaluated the palliative care at 6 and 9 months (or death). Families rated quality of

#### Source

Hanson LC, Zimmerman S, Song M, Lin F, Rosemond C, Carey TS, Mitchell SL. Effect of the Goals of Care Intervention for Advanced Dementia A Randomized Clinical Trial. *JAMA Intern Med.* 2017;177(1):24-31

[doi:10.1001/jamainternmed.2016.7031](https://doi.org/10.1001/jamainternmed.2016.7031)

symptom management using Symptom Management at the End of Life in Dementia (SM-EOLD) instrument and Satisfaction with Care at the End of Life in Dementia (SWC-EOLD) instrument.

Resident-family dyads were the primary unit of analysis, and all analyses used intention-to-treat assignment. Intraclass correlations were considered at 2 levels: residents clustered within nursing homes, and repeated measures for the same individual over time. A generalized mixed effects model with a random slope and intercept was fit to control the variation and correlation. Cox proportional hazards were used to analyze resident survival times.

### **Key Findings**

- Participant characteristics did not differ between study arms.
- Communication and decision making: The intervention group decision makers reported a better overall scores on the 10-point QOC questionnaire at 3 months compared to the control group (6.0 vs. 5.6,  $p=0.05$ ), this corresponded to higher subscale ratings of end-of-life communication for the intervention group (3.7 vs. 3.0,  $p=0.02$ ). The intervention group decision makers reported a perceived greater concordance with providers on the primary goal of care (88.4% vs. 71.2%,  $p=0.001$ ). Comfort was increasingly the primary goal of care over time for both groups. Intervention and control decision makers did not differ on Advance Care Planning Problem scores, however, but the discussion of residents' preferences to guide treatment was relatively infrequent
- Quality of palliative care: The ratings for SWC-EOLD and SM-EOLD did not differ among groups. Intervention group residents had more palliative care domains addressed in treatment plan at month 6 (5.6 vs. 4.7,  $p=0.02$ ). The goals of care documentation increased at 6months (91% vs. 42%,  $P < .001$ ), and at the final assessment (95% vs. 52%,  $P < .001$ ). The intervention group had more MOST order set completed by clinicians (35% vs. 16%,  $p=0.05$ ). Adjusting for person-days at risk, residents in the intervention group were half as likely to experience hospital transfers (0.078 vs. 0.163 transfers per 90 person-days; RR, 0.47; 95% CI, 0.26-0.88).

### **Limitations**

- All study sites were in a single state, the effectiveness of the GOC intervention may not be generalizable to other regions
- Family decision makers in the control group may have been prompted by study questions to discuss goals of care with clinicians, potentially reducing the measured effects of the intervention.
- Study findings apply to a long-stay population of residents who live in the nursing home and should not be generalized to the short-stay rehabilitation population.

### **Final Thoughts**

The GOC decision intervention improved the quality of communication between healthcare providers and family decision makers concerning end-of-life care. While comfort was prioritized in both intervention and control groups, the family decision makers in the intervention group experienced improved communication and confidence that there was goal concordance with healthcare providers. While the intervention relied on existing procedures, the GOC approach was shown to encourage effective communication and family involvement with treatment plans leading to improved palliative and end-of-life care.