PROJECT INFORMATION

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Testing a Way to Help Patients with Dementia and Their Caregivers Set Goals for Care

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Organization

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What was the research about?

Dementia is a health problem that can cause memory loss, trouble doing daily tasks, and behavioral problems. Sometimes patients with dementia and their caregivers have goals for patients that their usual medical care doesn't include. For example, caregivers may want to maintain patients' social activities in the community. They may also want patients to continue to live at home.

The research team wanted to test a process called Goal Attainment Scaling, or GAS, to see if patients and their caregivers could identify, set, and meet goals that were important to them. The team also wanted to see if GAS was valuable to patients and their caregivers.

What were the results?

Patients and their caregivers were able to use GAS to set goals that mattered most to them. Most goals were not medical. The goals focused on patient quality of life as well as caregiver health and well-being. When surveyed at 6 and 12 months, 75 percent of patients and caregivers said that they met the goals they set, and 96 percent said that the goals were meaningful. Further, 80 percent of patients and caregivers said that GAS captured something different from goals set by usual medical care.

Who was in the study?

The main part of the study included 101 pairs of patients with dementia and their caregivers. The

research team recruited these pairs from a dementia care program in Los Angeles.

Of the patients, 60 percent were white, 19 percent were black, and 6 percent were other races; 15 percent were Hispanic. The average patient age was 83. On average, patients had a moderate level of dementia. Patients with moderate dementia have increased confusion and more memory loss than earlier stages of the health problem.

Among caregivers, 57 percent were the patient's child, and 32 percent were the patient's spouse. Also, 70 percent lived with the patient. The average caregiver age was 62.

What did the research team do?

To develop the GAS process, the research team first interviewed 7 patients and 36 caregivers about what types of goals were most important. Then they created a list of goals from all the groups. To test GAS, the team had 6 patients and 26 caregivers choose important personal goals from the list or add new goals.

In the main part of the study, the team tested GAS in a dementia care program. In this part, 101 patient-caregiver pairs chose goals they felt were most important. Then, they worked with care managers to incorporate those goals into patients' care. The team talked to patients and caregivers 6 months and 12 months later to see if

- They had met their goals
- They thought the goals were meaningful
- The goals they had set with GAS were different from goals set previously during usual medical care

What were the limits of the study?

The research team tested GAS in only one dementia care program in Los Angeles. The team doesn't know if GAS will work in other places. Most patients in the study had dementia that was too severe to let them set goals for themselves, so caregivers set most of the goals. The results might be different for patients with milder dementia who are more able to take part.

Future research could see if other settings providing dementia care can use GAS to set and meet goals. Research could also test GAS with other types of clinicians, such as social workers and community health coaches. Finally, researchers could see how GAS works for patients with milder dementia or for patients with other long-term health problems.

How can people use the results?

Dementia care centers can offer the GAS process to work with patients and their caregivers so that care can help them meet the goals that matter most to them.

To learn more about this project, visit www.pcori.org/Reuben133.