Champions Study: Caregivers Sharing Meaningful Priorities for Patients

UNIVERSITY OF MARYLAND, SCHOOL OF PHARMACY

THE PURPOSE

To understand how family members prioritize decisions they need to make for their loved ones.

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Name of Project | Champions Study: Caregivers Sharing Meaningful Priorities for Patients

Study Sponsor | University of Maryland, School of Pharmacy

Total number of participants to-date | 210

Timeline of the project | 2 years

Funder | Agency for Research and Healthcare Quality

Target population | Family caregivers whose loved ones have Alzheimer's disease or related dementia

WHAT DID PEOPLE DO IF THEY WERE INVOLVED WITH THE PROJECT?

Family caregivers participated either in focus groups, interviews, or an online survey about their care management decision-making about their loved one's journey with dementia. They also provided feedback on the wording, design and meaning of the questions that were developed.

WHAT DID PARTICIPANTS TAKE AWAY FROM THEIR INVOLVEMENT?

Caregivers were able to discuss, reflect, and prioritize how different decisions are "negotiable" at different points in their loved ones' care.

WHAT ISSUES OR FINDINGS WERE DISCOVERED DURING THE PROJECT?

Finding: Family caregivers prioritize their own emotions and navigating family dynamics over dealing with their care recipient's reaction to their diagnosis – they also prioritize different care management or treatment goals based on their own lived experiences.

Application for senior living professionals: Family members need unique forms of support and conversation that are emotion-based, not only service-based, within different parts of their journey. This is governed by who they are and their lived experiences, not by what stage or disease their loved one is in.

WHAT ARE FUTURE DIRECTIONS AND OPPORTUNITIES FOR PARTNERSHIPS?

The survey tool that was designed and implemented to family caregivers could potentially be developed into a shared decision-making process that would be available for use.

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