

Q&A with Carol J Whitlatch, PhD

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What was the premise for your early studies that were the basis for SHARE?

Our motivation for early studies was that there were no programs that were specifically designed to meet the needs of both the person with dementia and their family members. Many programs focused on the person with early-stage dementia but there was no direct help for the person with dementia together with their family. At that time, our research focused on understanding how families communicate and work together during the stressful period when a family member is first diagnosed with early-stage dementia.

What did those early studies reveal?

In our early studies we asked people with dementia how they wanted to be cared for and we learned that their families did not always know or understand their relative's values and preferences for care. Families said that they wished there was a way to talk about these differences in perspectives and so we designed the early SHARE intervention to meet this need. We brought families together to listen to the person with dementia's desires and needs for their care.

How were the studies carried out?

With foundation and federal funding, for almost twenty years, we worked with families in San Francisco, Cleveland area, Toledo, San Diego and Northern Virginia. We were able to enroll over 500 families through Alzheimer's Association chapters, caregiver resource centers and private practitioners. We conducted program evaluations as well as randomized controlled trials. Participants in the control group were offered a standard session with a discussion of resources and information about the disease. Those in the SHARE program were offered six sessions with the family taking part in the discussion. We found that those who participated in SHARE had better outcomes in increased use of services, were able to construct a balanced care plan, and had improved communication with family caregivers.

What makes the SHARE program different than other early-stage interventions?

The innovation of the SHARE program is that, based on the research, the individual with early-stage dementia is able to voice opinions and make decisions about their care preferences. We found that they feel a sense of relief that they have a voice in creating their future and feel confident that their family will honor their wishes. They report higher program satisfaction and engagement than others that didn't participate in SHARE.

Why is the SHARE program so effective?

One of the unique and useful features of SHARE is it helps families to recognize the potential burden of care that a caregiver will face as the disease progresses. We found that when we created a visual representation of all the care tasks that the caregivers would be responsible for, it really brought to life the enormity of the potential physical and emotional stress that a caregiver could experience. We created a board and magnets, which later evolved into an app, which listed tasks that could be assigned to either their caregiver, family and friends or service providers. Overwhelmingly the person with dementia assigned most, if not all, of the care tasks to their family caregiver. When the person with dementia and caregiver looked at the long list of tasks, both realized that there was too much burden on the caregiver. Once families accepted that the caregiver could not do it all, they were able to put together a plan of care that was manageable and agreed upon by everyone.

How did the SHARE App come about?

We received such positive reactions to SHARE that we wanted to make it available to the practitioners who work with early-stage families. We developed an app that helped to simplify the process in developing the care plan. The app easily identifies the assignment of work tasks, organizes all of the materials a SHARE counselor needs to conduct all six sessions, and stores case notes and other program materials.

What feedback have you received about SHARE?

We have found that what was once an overwhelming and stressful experience has become more manageable and has given people with early-stage dementia and their families hope about their future. SHARE counselors find the program fills a gap in program delivery and is giving them the tools to address the sensitive topics that newly diagnosed individuals with dementia and their families confront. We are very encouraged by the positive reaction and interest from the caregiving and human services communities.