

Case Study: Baylor Scott & White Health's Family Caregiver Program

An Evidence-Based Caregiver Intervention Adapted for an Integrated Health Care System

"We were motivated to develop the capacity as an organization to make this available to people who would benefit, and to alleviate the stressors we were seeing in primary care related to dementia."

Alan B. Stevens, PhD, Director, Center for Applied Health Research, Baylor Scott & White Health

BACKGROUND

Baylor Scott & White Health (BSWH) developed an evidence-based multi-component program to support family caregivers of people living with dementia. Caregivers enrolled in the Family Caregiver Program (FCP) received six months of assessment and support, training in dementia caregiving skills, and educational materials. The program was an effort to translate the results of Resources for Enhancing Alzheimer's Caregiver Health II¹ (REACH II) to an integrated non-profit health care system setting.

Initial funding for the program was provided by the Rosalynn Carter Institute, Johnson & Johnson, and Scott & White Health, supporting a successful pilot study in one 636-bed hospital and a large ambulatory primary care clinic.² In 2011, Scott & White Health invested an additional \$150,000 to continue and expand the program to a second ambulatory clinic. Although the FCP yielded positive outcomes for the caregivers it served, the program was closed in 2015 due to difficulties recruiting new participants in the health care setting. Caregivers were resistant to considering their own needs while their loved one was receiving medical attention for an acute need. The experience shed valuable light on caregivers' willingness and capacity to engage in hospital-based support programs at times of stress, suggesting that community-based outreach may have greater success.

IN BRIEF: DEMENTIA CARE AT BAYLOR SCOTT & WHITE HEALTH

Program Name: Family Caregiver Program

Institutional Home: BSWH is the largest not-for-profit health care system in Texas, resulting from the 2013 merger of Baylor Health System and Scott & White Health.

Location: Central Texas (Waco, Temple)

Patient Population: Caregivers were eligible to enroll in the FCP if they provided 10 or more hours of direct care per week for a family member with any stage of dementia. The program was offered to English- and Spanish-speaking participants; access to a telephone and residence in one of the counties served by the health system were required.

Caregiver support: Assessment and support, training in dementia caregiving skills, educational materials.

Staffing Model: Three Dementia Care Specialists (DCS): one for each of two ambulatory clinics and one for the hospital setting, and a program manager to support inpatient identification and service to family caregivers. A typical caseload was 12 caregivers per DCS.

Funding Model: Philanthropy; organizational support

APPROACH

The FCP identified and approached caregivers of people living with dementia during a hospital stay or ambulatory visit of the person with dementia. In the clinics, providers referred the family caregiver to the FCP. In the hospital, patients with dementia were identified using reports run on the hospital census. Two key questions were embedded into the hospital admissions EHR infrastructure: if a nurse identified a person as having dementia, or being a caregiver of a person with dementia, an automatic display would prompt the nurse to give the caregiver a Caregiver Packet, the program's primary recruitment tool.

The FCP also enlisted the support of staff in the hospital and clinic settings. These champions—300 nurses in the hospital, 65 nurses, and 20 physicians in a large outpatient clinic—received information about the program and were encouraged to foster identification of family caregivers and adoption of the program by incoming staff. The FCP launched in stages, beginning with the 3 nursing units with the highest volume of geriatric patients, and gradually reaching all 9 units of the hospital. A phased-in approach was also used in the primary care clinics.

Once a patient was identified, an FCP staff member, known as a Dementia Care Specialist (DCS), would visit the caregiver in the hospital or clinic room and discuss enrollment in the program. Family caregivers who chose to enroll in the 6-month program were offered up to 5 in-person visits with a DCS, telephone support, and educational materials. The original REACH II intervention provided 9 in-home visits and 3 telephone sessions, but like other translations, these numbers were reduced in response to resource constraints on providing non-billable services, and to make it more feasible for caregivers. Visits were conducted in the clinics, but could be in the home if needed for caregivers at higher risk, and additional visits could be provided to address special needs. All services were offered during normal business hours only.

DCSs were either social workers or graduate students working toward related qualifications, and received training to deliver the REACH II intervention and supervision by a REACH II principal investigator, Dr. Alan Stevens. The team at BSWH has since developed a 1.5-day standardized training and certification program for Dementia Care Specialists, which is available for community-based organizations serving caregivers.³

The first phase of the FCP comprised an initial assessment, in which the DCS met the family and learned about their unique caregiving situation through a formal interview. Using tools developed for the REACH II intervention, DCSs asked caregivers questions about their quality of life and completed a risk assessment. Results of the risk assessment were used to categorize caregivers into low-, moderate-, and high-risk groups, and to guide customization of the subsequent intervention, both in terms of content and frequency of visits or telephone interactions. Caregivers also answered the Stanford Patient Education Research Center Healthcare Utilization Measure.

Following the initial assessment, the DCS mailed caregivers an individualized Family Profile, to serve as a roadmap to interventions most relevant to that family. The profile was tailored to the specific needs identified in the risk assessment. Caregivers would also receive a Caregiver's Notebook with a wealth of additional resources to support their needs. In partnership with the local Area Agency on Aging, the DCS also referred the caregiver to the necessary community services. FCP staff developed a streamlined referral system allowing them to automatically connect enrolled caregivers to the Central Texas Area Agency on Aging for formal services such as access to respite care, home modifications, mental health counseling, or advice on benefits, for example. This first phase of the program took place in the first month after enrollment.

In the next phase, the DCS set goals with the caregivers, engaged them in assessing safety and other priorities, coached them in skill building and practice, and followed up with telephone contact. The DCS could engage caregivers using simple instruction, role playing, and problem-solving techniques. The nature and frequency of contacts depended on the caregiver's level of risk. High-risk patients would receive monthly contacts, patients at medium risk would receive contact every other month, and low-risk caregivers would have contact with their DCS once every three months for the duration of the program. The program did not include home video technology or telephone-based support groups that were part of the original REACH II intervention, but staff did encourage caregivers to attend local support groups. At the end of the six-month program, caregivers completed a second risk assessment and a satisfaction survey.

The FCP did not officially document its services in the health record, but the DCS routinely provided updates on the overall family caregiving situation to the clinic staff who referred the family caregiver.

RESULTS TO DATE

The health system's evaluation of the FCP found that out of eligible caregivers invited to enroll, 35 percent were enrolled in the FCP (164 caregivers in total). Stratification of the number throughout the implementation phase shows that enrollment percentages increased as the program was rolled out. However, more than half of these caregivers did not complete the course and final evaluation for a variety of reasons.

For caregivers that completed the six-month FCP intervention (72 in total), the study found significantly positive improvements in the caregiver's pre- and post-risk assessment scores. The average risk score decreased from a medium- to low-risk level: a change driven by significant decreases in caregiver burden and dementia-related behaviors, and significant increases in care recipient safety. Over 82 percent of caregivers agreed that the services were helpful.

TOOLS

- EHR caregiver identification tool: created in collaboration with technology specialists from Scott & White Siemens information technology team and the nursing staff
- Caregiver Packet: a recruitment brochure for caregivers
- REACH II Quality of Life Assessment, comprised of five domains:
 - Caregiver Burden measured using the twelve-item Zarit Caregiver Burden Interview⁴
 - Depression measured by self-report on the ten-item version of the Center for Epidemiologic Studies Depression scale⁵
 - Dementia-related behaviors measured by three questions (memory, depression, and disruption) from the Revised Memory and Problem Behavior Checklist⁶
 - Social support measures using the REACH II Social Support Composite¹
 - Self-care measured using the REACH II Self-Care Composite¹
- REACH II Risk Assessment Measure (adapted from original 59-item assessment² for the FCP): a 16-item questionnaire for identifying and prioritizing caregiver risk in 6 domains: depressive symptomatology, burden, self-care, social support, patient dementia-related behaviors, and safety
- Stanford Patient Education Research Center Healthcare Utilization Measure
- Formal training and certification for Dementia Care Specialists in the REACH II intervention³
- Caregiver's Notebook: extracted from the REACH II intervention manuals and reformatted for consumers, the notebook provides information on home safety, social support, managing stress, finding things to enjoy, healthy living, understanding feelings, skillful communication, relating memory problems to behaviors, and legal and medical information²
- Family Profile: designed to tailor the intervention to the specific risks/needs of the caregiving family²
- Automatic referrals to the local Area Agency on Aging (AAA) for services

LESSONS LEARNED

- **Build and maintain strong partnerships:** The success of the program depended on strong internal partnerships with leadership at Scott & White Health. The program aligned with the organization's mission and vision, and strong external partnerships with community partners at the Central Texas AAA ensured that caregivers could efficiently access needed services.
- **Engage caregivers outside the health care setting, at times of low stress:** Family caregivers lacked interest in a program that was focused on their needs rather than the needs of the family member with dementia, particularly while their loved one was receiving medical attention for an acute need. This meant that the FCP was investing more resources in identifying and recruiting caregivers than they were in delivering services, contributing to the closure of the program.
- **Community-based outreach may have more success:** REACH II interventions have had considerably more success in recruiting caregivers through community-based organizations such as the Alzheimer's Association or local Area Agency on Aging. A population health management approach could also be more effective, suggests Dr. Stevens. With better family caregiver representation in the EHR, caregivers could be engaged at times of low stress to give them the services and skills training they need. "This is more in line with prevention and we believe fits better with population health approaches to care employed by ACOs and health care payers," said Dr. Stevens.

- 1 Belle, S.H., Burgio, L., Burns, R., Coon, D., Czaja, S.J., Gallagher-Thompson, D., Zhang, S. "Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups: A Randomized, Controlled Trial," *Ann Intern Med*, 2006; 145(10): 727-738. Web access: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585490/>.
- 2 Stevens, A.B., Smith, E.R., Trickett, L.R.A., McGhee, R. "Implementing an Evidence-based Caregiver Intervention Within an Integrated Healthcare System," *Transl Behav Med*, 2012; 2(2): 218-227. Web access: <http://doi.org/10.1007/s13142-012-0132-9>.
- 3 Organizations interested in hosting a REACH II training using the materials and protocol developed by BSWH may contact Thomas Birchfield at t.r.birchfield@gmail.com.
- 4 Information on the development and validation of the Zarit Burden Interview, together with instructions on how to access and use the assessment tool, is available at <http://mapi-trust.org/questionnaires/zbi>.
- 5 Information on the CES-D scale is available at <http://cesd-r.com>.
- 6 The full Revised Memory and Behavior Checklist is available at https://www.alz.org/national/documents/C_ASSESS-RevisedMemoryandBehCheck.pdf.

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Case study prepared by Saskia Siderow, MPH, Managing Director, Ormond House LLC
Content based on information provided by Alan Stevens, PhD, Director, Center for Applied Health Research, Baylor Scott & White Health