

Findings from the Caregiver Support Referral Pilot

The Caregiver Support Referral Pilot was a unique partnership between the Amherst H. Wilder Foundation's (Wilder's) Caregiver Services and the Entira Family Clinics. This pilot was established to enhance the health and well-being of patients and their caregivers by connecting caregivers with support and resources at the time of a health visit. It is believed to be the first time health care clinics in Minnesota have implemented a strategy to directly refer patients and their families to a home and community-based service provider offering caregiver services. Funding for the pilot was provided through a two-year grant from Medtronic Foundation's PatientLink initiative intending to build awareness, educate and advocate on behalf of patients and their families to improve the lives of people with chronic diseases.

A 2015 AARP caregiving study found that 84 percent of caregivers said they could use more information or help on caregiving topics, yet only one-third of caregivers said they have been asked about what they need to provide care. Fewer caregivers (16%) said they have been asked by a health care provider about what they need to care for themselves (<http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html>).

By identifying caregivers of older adults in the clinic setting during regular health care visits and introducing caregiving supports, the pilot sought to: develop effective strategies for identifying and engaging patients and their families in a clinical setting regarding potential caregiver needs, better support health goals in the patient's home, achieve greater comfort and satisfaction with care, and reduce avoidable hospital admissions. In addition, caregivers were expected to benefit from reduced stress, increased confidence in their caregiving role, and new skills that would help them to recognize their own needs, set effective boundaries, and practice self-care. By the conclusion of the project, partners had worked out methods for effective engagement in clinical settings and gathered preliminary data to partially support aims related to the support of the caregiver. The pilot, however, was unable to collect sufficient health-related data to support project aims related to the support of the patient's health goals.

About the pilot

Wilder established a referral process with all 12 Entira Family Clinics (Entira) primary care clinics. Entira staff referred patients and their families to Wilder's Caregiver Services after determining that a patient's caregiver may be in need of supports, assistance in accessing resources, or related services. Within 48 hours of referral notification, Wilder contacted the family caregiver to discuss service options and needs. If caregivers reported immediate needs, appropriate services were identified and arranged. If caregivers declined immediate supports, but were open to follow-up, regular telephone check-in calls were scheduled.

From March 1, 2013 through April 1, 2015, 75 caregivers were referred to Wilder's Caregiver Services. Half of those caregivers (49%) were caring for a spouse, 31 percent were caring for a parent, and 20 percent were caring for another family member. Of the caregivers referred to Wilder, the most commonly reported health condition of care recipients was dementia or another cognitive impairment (45%), followed by cardiovascular disease or hypertension (12%).

Services received

Of the 75 caregivers referred, 62 caregivers (83%) received support from Wilder's Caregiver Services social workers. The number of subsequent contacts per household ranged from 1 to 26, averaging between four and five ongoing contacts with Wilder. During each contact, caregivers received information or an offer of assistance. In addition:

- 15% completed a service assessment to determine best potential service options
- 20% received extensive phone consultation and problem solving assistance
- 3% participated in Memory Club, a support group for people with early-stage dementia and their care partners

Lessons learned

Families face many challenges around caring for an older adult, and the clinic offers a trusted setting to introduce the benefits of caregiver services. Implementing the pilot highlighted the following lessons.

What worked well

- Establishing data exchange protocols and procedures for the purpose of making and receiving referrals
- Ensuring timely follow up – Entira's care managers typically received feedback from Wilder staff regarding the caregiver phone consultation within one week of the referral
- Empowering all Entira staff to make a referral helped to minimize barriers to reaching potential caregivers

Challenges

Wilder and Entira continue to work together to address these challenges as the partnership continues:

- Addressing both patient and caregiver reluctance to engage caregiver support. Patients may fear becoming a burden to caregivers, which can prevent caregivers from accessing supports; caregivers may be resistant to help if they feel pressured or have not developed trust in Wilder.

- Identifying appropriate metrics for assessing change in the patient experience via enhanced caregiver supports.
- Establishing data sharing processes that allow partners to look at patient health outcomes that may have been influenced by the receipt of caregiver services.

Key informant interviews and case reviews conducted at the conclusion of the project with Wilder and Entira professional staff suggest modest success in meeting the original goals around improved patient health and well-being. Respondents see significant potential for future benefit through the modification of clinical practice and engagement strategies to better integrate community-based supports with medical services. These positive findings related to systems change, however, are not sufficient in and of themselves. Further effort is needed to better understand the impact of such services on patients and their caregivers. Partners are motivated by what has been learned in the pilot to continue and expand the current collaboration using this new model of service delivery.

Next steps

Early referral for caregivers shows promise. Both Wilder and Entira are committed to continuing the partnership. In fact, the partners believe the partnership is both replicable and sustainable. Looking ahead, Wilder and Entira will:

- **Explore the potential for having a caregiver services staff member available on-site at one or more clinics** on a limited basis. This will help determine whether or not a “warm handoff” to an individual on-site may result in better acceptance of, and enrollment in, caregiver supports and services.
- **Identify additional research needs.** For example, additional research could determine whether caregivers who are well supported are able to sustain their caregiving for longer periods, thus delaying institutionalization costs. Controlled studies are necessary to determine whether improved caregiver support can reduce unnecessary hospital admissions or other forms of crisis care, and the extent to which well-supported caregivers improve patient outcomes in the home.

The value of caregiving services

In March 2014, Wilder Research conducted telephone interviews with 54 participants in Wilder's Caregiver Services that included some Entira referral caregivers. When asked which aspects of Wilder's Caregiver Services they found most valuable, caregivers mentioned three things most frequently:

- Opportunities to get to know other caregivers, share experiences, and gain mutual support
- Advice and support received from Wilder's social workers
- Information about resources available in the community to support caregivers and how to obtain them

Results from the survey show that caregivers:

- Increased their knowledge and understanding of what it means to be a caregiver (94%)
- Improved their caregiving skills (89%)
- Gained confidence about handling their caregiving responsibilities (89%)
- Were better able to meet the needs of the person they care for (85%)
- Were better able to take care of their own health (70%)

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For more information

This summary presents highlights of the *Caregiver Patient Empowerment Project*. For more information about this project, contact Maureen Kenney, Wilder Caregiving Services, at 651-280-2509.

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