

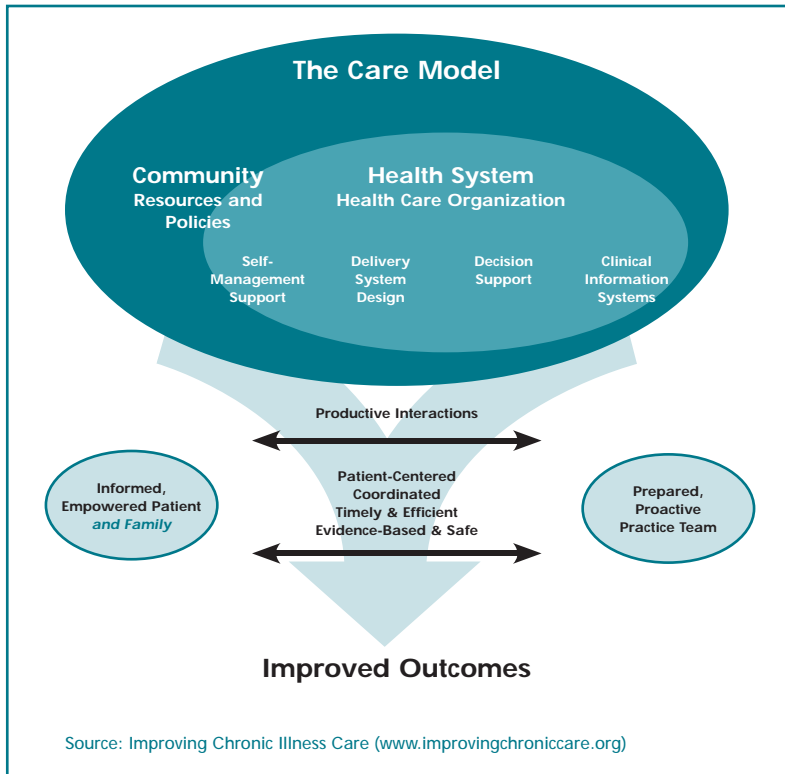
Chronic care in the U.S. is fragmented, discontinuous, difficult to access, inefficient, unsafe and expensive.

Integration of Caregivers in the Health System: The Guided Care Intervention

Jennifer Wolff, PhD
Assistant Professor, Department of Health Policy & Management
Johns Hopkins University Medical Center

Chronic care in the U.S. is fragmented, discontinuous, difficult to access, inefficient, unsafe and expensive. As a result, there is a growing consensus regarding the need for health care delivery systems that more effectively support patients' chronic care. Several innovations that have individually proven to be successful include disease management, case management, transitional care, self-management, lifestyle modification, caregiver education and support, and geriatric evaluation and management. However, each of these innovations addresses only a subset of patients' needs. There is increasing interest in more comprehensive, multifaceted interventions that simultaneously address physician practice, patient self management, and support for patients' families. "Guided Care" is one such intervention.

The Model. "Guided Care" is a model of delivering chronic care for multimorbid older adults that explicitly recognizes and includes patients' family caregivers. In Guided Care, a registered nurse who has completed a supplemental educational curriculum and joined a primary care practice works closely with several primary care physicians (PCPs). Together they address the chronic care needs of 50 to 60 patients who have multiple diagnoses and are at high risk for heavy use of health services during the coming year. Using a web-accessible electronic health record (EHR), the Guided Care nurse collaborates with the patient's PCP to facilitate



eight clinical processes: (1) Assessing the patient and primary caregiver at home, (2) creating an evidence-based care plan, (3) promoting patient self-management, (4) proactively monitoring the patient's conditions, (5) coaching the patient to practice healthy behaviors, (6) coordinating the patient's transitions between sites and providers of care, (7) educating and supporting the caregiver and (8) facilitating access to community resources. A more detailed description of Guided Care has been published (Boyd, et al. 2007; in press).

Trial. A cluster-randomized trial of Guided Care is now underway in the Baltimore-Washington area. After completing a baseline interview with a professional survey research firm, patients and their primary caregivers were randomized by PCP to either Guided Care or usual care. A variety of health-related outcomes are being assessed for patients and their primary caregivers at 6 and 18 months follow-up. To establish the evidence needed to disseminate Guided Care, information about its financial viability and attractiveness to health care providers and insurers is also being collected.

Outcomes

Outcome measurement at 18 mos
(n ~ 580 survivors, complete data)

Patient

- Functional ability
- Affect
- General health
- Satisfaction with care
- Use/cost of health services
- Mortality

Primary caregiver

- Burden/benefits of caregiving
- Affect
- Satisfaction with care
- Use/cost of health services
- Financial status

Providers

- PCP satisfaction
- PC office environment
- GCN satisfaction

Insurers

- Volume of services
- Cost of services
- Quality of care

Caregiver Definition. Because Guided Care is a lifetime model of care (patients are not discharged), the term “caregiver” is defined broadly as a relative or unpaid friend assisting the patient with health-related tasks. This definition reflects the belief that establishing productive working relationships with patients’ informal supports will mutually benefit both caregivers and patient care, and better prepare all involved parties when patients experience setbacks in their health. Because some individuals may not identify with the term “caregiver” and may even be offended by its use, in Guided Care the term “families and friends” is used whenever possible.

The “Guided Care Program for Families and Friends” includes the following components: (1) An initial in-person meeting between the nurse and the person the patient identifies as helping the most with health-related tasks, (2) education and referral to community resources, (3) ongoing “coaching” related to patients’ health-related needs, (4) a six-session Guided Care Nurse-facilitated Workshop, followed by (5) monthly Guided Care Nurse-facilitated Support Group meetings. Guided Care Nurses conduct all components of the Guided Care Program for Families and Friends; however, participation in the program is voluntary for patients’ families and friends. Some of these components (e.g., education and referral) may be available as parts of usual primary care in some practices, others are more particular to Guided Care and are therefore further described.

The first relatively unique feature is that the Guided Care Nurse meets with the family member or unpaid friend identified by the patient as assisting

“the most” with health-related tasks. The first meeting lasts on average 30 minutes and has several objectives, including: (1) to begin a working relationship between the Guided Care Nurse and the patient’s informal supports, (2) to allow the patient’s family or friend to state their own needs or concerns, and (3) to identify and facilitate relevant education and community services referral. Summary information from the meeting and intake form is entered into patient’s EHR and evidence-based care plan.

Each nurse also facilitates a Workshop once a week for six weeks, followed by ongoing monthly Support Group meetings, for any interested and involved families or friends of their patients. Each Workshop session is 90 minutes in duration and focuses on a particular skill, coping technique or issue related to assisting a chronically ill older adult. The Support Group meetings reinforce skills and techniques discussed in the Workshop, cultivate communication between nurses and families and friends of their patients, and provide families the opportunity to share their experiences and emotional support. Each Support Group decides for itself how to structure its time (e.g., whether to invite speakers) and when to hold the meetings.

Guided Care is a multifaceted model of care. To be successful, nurses must manage many responsibilities without letting any single function dominate. To this end, the Program for Family and Friends was developed to be flexible (e.g., the in-person meeting may be replaced by a telephone meeting for working caregivers) because some families or friends may not be able to fully participate in all aspects of the program. It is our hope that improved quality of patients’ health care in conjunction with more explicit recognition and support of their family caregivers will benefit patients, families, as well as valued patient care outcomes.

References

Boyd, C.M., Boulton, C., Shadmi, E., Leff, B., Brager, R., Dunbar, L., Wolff, J. & Wegener, S. (in press). Guided care for multi-morbid older adults. *The Gerontologist*.

