

Family Caregiving During Healthy Aging and Illness

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FAMILY CAREGIVERS ARE INEXTRICABLY nested in health care. Upon return home after an important physician visit, a patient may encounter questions from a spouse or other loved one. For many patients, family members provide direct accompaniment to the physician and actively participate in informed consent and other clinical decisions; for some, the caregiver is a designated legal proxy decision-maker. There is variety in how these patient-caregiver relationships form and develop over time; some individuals clearly identify who will help long before the help is needed whereas others are forced to recruit family caregivers amidst an unexpected and urgent crisis. Be it routine, a crisis or advanced care planning, there are always opportunities to enhance the process of patient, caregiver and clinician working together.

The **Institute for Healthcare Improvement (IHI)** proposes that all initiatives to enhance quality should concurrently address three facets of a “Triple Aim,” including: “better care for individuals, better health for populations, and lower per capita costs.”¹ In Rhode Island, estimates suggest that there are over 100,000 individuals providing substantive unpaid family caregiving, translating into millions of dollars of free health care to the seriously ill. Any quality initiative targeting an illness, such as post-stroke rehabilitation, or an environment, such as hospital service use, must attend to the role of the family caregiver as an essential component of improving health care quality. The question is: what opportunities currently exist for better integration of family caregivers into routine health maintenance and acute patient care settings?

Enhancing patient care by incorporating family caregivers must address the public health context of caregiving,² including health risks for family caregivers, and caregivers’ instrumental needs. There is growing concern that the chronic stressors associated with protracted family caregiving pose health risks. Specifically, Family caregivers report worse health than non-caregivers,^{3,4} engage in fewer health-

promoting behaviors³ and have worse medication compliance.⁵ In 1999, Schulz reported a 63% higher mortality risk for strained spousal caregivers.⁶ In other studies, caregiving for a hospitalized patient has been shown to be an independent risk factor for caregiver death; and, dementia caregivers have the highest risk,⁴ possibly due to poor self-care combined with distress while faced with dementia-related behavioral problems in care recipients.⁷ The majority of family caregivers assisting an individual hospitalized for behavioral disturbance associated with dementia report depressive symptoms suggesting clinical-level severity.⁸ Based on data such as these, in their 2007 publication “Framing the Public Health of Caregiving,” Talley and Crews propose a triadic model to conceptualize the role of the family caregiver as an equal and necessary collaborator.² In this model, the care recipient, the family caregiver and the clinician are partnered within a healthcare context constrained by limitations imposed by the illness, regional practice patterns, professional reimbursement and other system-level factors. This triadic model may help shape future public health attention specific to caregivers.

Empirical tests of the risks and potential benefits of strategies to build a stronger patient-caregiver-clinician alliance are on the near horizon.

How might the triadic model of patient-clinician-caregiver be actualized? Most clinicians likely see several family caregivers each day and devote a significant portion of patient-contact time to interacting with caregivers. Amidst these encounters, the clinician may informally note the family caregiver’s functional capacity, current stress, and risk for suc-

cumbing to excessive burden or symptoms of depression.⁹ While completing this informal assessment, the clinician might suggest new services for the caregiver and may also complete a brief chart notation as a reminder to follow-up regarding family resources at the next patient encounter; in addition, there are other methods by which the patient-clinician-caregiver alliance can be fostered.

Opportunities exist in both outpatient and hospital practice to conduct a formal assessment of caregiver health and functioning. In the outpatient setting, a screening measure for depression or burden can be completed prior to the clinician encounter;¹⁰ the results of this screening tool can be reviewed by the clinician and incorporated into plans for providing the family caregiver with instrumental assistance, such as home care, or individualized clinical follow-up specifically for the family caregiver, such as a visit to primary care or a referral to social work or psychiatry if indicated. In the hospital setting, to complement the functional and mobility assessments that patients may complete in order to plan discharge services to home care or skilled residential treatment, similar tools can be used with family caregivers to determine whether the home environment is suitable for in-home nursing or physical therapy; such assessments could lead to improved aftercare matching and increased potential to transition patients directly home with enhanced support rather than through nursing home treatment. More importantly, a hospital-based caregiver assessment might prevent discharge to a homecare environment currently unprepared for success with such treatments; avoiding such a conflict could prevent excessive stress to the family caregiver and also reduce the risk of patient rehospitalization.

Increased educational opportunities are an alternative to completing formal or informal caregiver assessment during inpatient and outpatient clinical encounters. Education can build solidarity between patient, clinician and caregiver if opportunities are provided for the patient and caregiver to operationalize the information.

For example, if upon admission to a new outpatient program or hospital care environment, the patient and family caregiver are provided with an education brochure *plus* notification of a designated time at which the information will be reviewed in detail with a clinician; then, an iterative process can develop, leading to enhanced communication and care coordination.

Empirical tests of the risks and potential benefits of strategies to build a stronger patient-caregiver-clinician alliance are on the near horizon. Already there have been substantial efforts dedicated to improving post-hospital care transitions for patients at risk for rehospitalization due to illness such as congestive heart failure or hip fracture. This transitions intervention research has led to best practices that are now being adopted by the **Centers for Medicare and Medicaid Services (CMS)** as well as private insurance carriers, and mandated use of quality indicators are being written into new hospital contracts. Meanwhile, there is a growing spotlight on vulnerable patients who, due to cognitive impairment or other frailty, are less able to self-advocate during aftercare transitions. For these populations, there has been relatively sparse empirical testing of transition programs; however, new announcements from CMS and elsewhere are placing renewed emphasis on family caregivers as partners in quality improvement initiatives, particularly for vulnerable patients at risk for high utilization of health services.

Rather than wait for government entities and private insurers to issue guidelines to improve coordination of service use, several illness-specific advocacy groups such as the **American Cancer Society (ACS)** are developing new models now that enhance patient care by building patient-caregiver-clinician alliances. One such example is the Patient Navigator Program developed by ACS; this initiative seeks to match every newly-diagnosed

cancer patient with a specially-trained clinical “patient navigator.” The navigator’s job is to provide education, instrumental aid for communication with key clinical services, and emotional and cognitive support as the patient adjusts to the cancer staging and treatment process. The navigator seeks to complete these tasks in coordination with family caregivers; for those patients without a family caregiver to assist with instrumental support, the navigator accepts added responsibility.

When clinical outcomes are positive and a family caregiver is able to “retire” from a formal caregiver role and return to being spouse or adult child, there can be both relief and satisfaction. Unfortunately, many illnesses are progressive and caregiving responsibilities persist into the last chapters of a patient’s life. For some caregivers, entering bereavement is a relief whereas for others the death of the family member brings new unforeseen challenges regarding return to their own life anew. For clinicians who provide end-of-life care, there are opportunities here as well to promote caregiver health by encouraging caregiver self-care in anticipation of the terminal illness phase and after death.

In summary, there are many opportunities to enhance patient care by formally strengthening triadic patient-caregiver-clinician communication. Success with such endeavors has the potential to reduce health risks for caregivers, improve the quality of patient care, and result in lower health delivery costs. While awaiting the empirical testing of new models, there are steps clinicians, patients and family caregivers can take today. These steps include increased attention to educational materials for family caregivers, formal assessment of caregiver functioning prior to key role changes, and attention to developing new opportunities for caregivers and patients to collaboratively discuss care and treatment with clinicians.

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