

# Health Affairs

## Family Caregiving And Palliative Care: Closing The Policy Gap

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*Editor's note: Carol O'Shaughnessy also coauthored this post. This post is part of a periodic Health Affairs Blog [series on palliative care, health policy, and health reform](#). The series features essays adapted from and drawing on an upcoming volume, [Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Care Reform](#), in which clinicians, researchers and policy leaders address 16 key areas where real-world policy options to improve access to quality palliative care could have a substantial role in improving value.*

Family caregivers — what would we do without them? So why can't we do more for and with them?

Many [studies](#) have demonstrated that family caregivers provide a wide range of essential care to people with serious chronic illnesses or disabilities — the same people who can benefit from palliative care applied as an ongoing approach to care, not just a hospital-based intervention.

It is family caregivers who are responsible for much of the complex care at home, including managing pain and other medications, monitoring equipment, and communicating with the palliative care team. To say that most family caregivers are not prepared to take on this demanding role is an understatement.

In theory palliative care practice supports the principle of person- and family-centered care, which addresses the needs of both the recipient of care and his or her caregiver, promotes communication and shared decision making as well as coordination and collaboration by health care delivery teams. While these concepts have been recognized and included in practice guidelines — for example, those established by the [National Consensus Project on Palliative Care](#) — they are often more an ideal than a reality.

But the practice arena is far ahead of the policy world. Support for family caregivers has largely been absent from policy discussions of palliative care, which focus on professional, clinical, regulatory, and financial issues. As palliative care moves “upstream,” that is, earlier in the course of illness, and into the “mainstream,” as part of standard medical care, it is essential to bring family caregivers into the discussion, hear their concerns, and develop meaningful policy responses.

**Gaps in Understanding about Palliative Care**

Thinking about the policy implications of addressing family caregivers' needs in palliative care practice must start with the reality that most patients and family caregivers do not know much about palliative care. In a [public opinion poll](#) conducted by the Center to Advance Palliative Care, only 3 percent of the respondents said that they were “knowledgeable” about palliative care.

People are often introduced to palliative care during a crisis, when it is difficult to integrate and accept new knowledge. If they do know something, their knowledge may be incomplete or inaccurate. And even when they do get appropriate information, they may choose to reject it.

Opening a discussion of palliative care brings up fears of abandonment, suspicions about financial reasons to reduce expensive treatments, concerns that death is imminent, guilt, and anger. Families are often said to be “in denial.”

But these deep-seated emotional reactions cannot be addressed with just a checklist or a short conversation. Health care professionals themselves are often uneasy in these discussions; they too are unprepared.

### **Reasons for Lack of Policy Support for Family Caregivers**

Family caregiving is a latecomer to the health care policy arena for a number of reasons. One reason is policymakers' fear that putting public support and resources toward this kind of care will lead family caregivers to reduce their own efforts. As [Bruce Vladeck](#) put it, with characteristic bluntness, “Policy makers have perceived the problem as one of trying to avoid paying for something that they have been accustomed to getting for free.”

As [numerous studies](#) have shown, families do not abandon their ill relatives when there is public support. Moreover, there is a huge cost to this “free” labor, in terms of the mental and physical health of caregivers, their immediate and long-term financial losses, and costs to employers when valued employees leave the workplace or cannot take on new responsibilities.

Another reason for this lack of serious attention has been that caregiving is often defined and measured in relatively simple and straightforward ways – helping with Activities of Daily Living (ADLs), such as bathing and dressing, and Instrumental Activities of Daily Living (IADLs), such as shopping and transportation. These measures were introduced in the 1950s and 1960s and a typical reaction has often been: “What’s so hard about that?” But these measures fail to take account of the increased level of specialized medical care at home, provided in large part by family caregivers.

Based on a national survey, the AARP Public Policy Institute and United Hospital Fund report, [“Home Alone: Family Caregivers Providing Complex Chronic Care,”](#) found that nearly half (46 percent) of all caregivers were performing one or more tasks like wound care, medication management, and operating medical equipment, in addition to ADLs and IADLs, without professional teaching or support. These tasks are likely to be among those required in palliative care at home.

A related reason may be the lack of standards and requirements for team-based care and a failure to appreciate its value in nonhospital settings. Interdisciplinary teams that include social workers are more likely to respond to the psychosocial needs of both patients and families and to be attuned to environmental and socioeconomic issues that affect caregiving. With the exception of integrated health care plans, the use of interdisciplinary team-based care is relatively rare, although there are some innovative models.

Policymakers anxious to control health care costs are beginning to recognize the important role that caregivers play in transitions from hospital to home. [Eric A. Coleman](#), a geriatrician, has pointed out that "...in the majority of care transitions, the patient and caregiver are the only common thread between sites of care and by default have been given the added responsibility of facilitating their care transitions, often without the necessary skills or confidence to do so."

Although the early transitional care models did not typically include attention to family caregivers, in recent years the caregiver's role and responsibilities have commanded more attention by policymakers and practitioners. One example is the recent addition to Boston University Medical Center's Project RED (Re-Engineered Discharge) of a new tool, developed in collaboration with the United Hospital Fund, called "[Understanding and Integrating Family Caregivers into the Re-Engineered Discharge](#)."

This tool sets out five steps for hospital staff to identify family caregivers, assess their strengths and limitations, integrate this information in a care plan, implement the RED post-hospital plan, and follow up. Although designed for hospital discharges, it can be used in any setting and formalizes attention to family caregivers.

### **Possible Future Actions**

A number of actions should be considered by payers, providers, caregiver organizations, and the research community to improve support for family caregivers providing palliative care. On the federal level, programs designed to improve care coordination such as Accountable Care Organizations and Patient-Centered Medical Homes, as well as Community Care Transition Programs, should add explicit attention to family caregivers in their protocols.

Short of having Medicare adopt a palliative care benefit (not a bad idea, just an unrealistic one), Medicare guidelines and conditions of participation for hospitals, skilled nursing facilities, and home health care agencies should explicitly recognize the need for training caregivers to provide the complex tasks that they are expected to do.

Family caregivers should be brought into the planning process as early as possible, so that there are no surprises at discharge and while the disease progresses. Part of this planning should include discussion of palliative care, where appropriate, introduced by skilled clinicians who can address spoken and unspoken concerns. This is not a one-time conversation, but an ongoing discussion.

At the state level, the expansion of Medicaid under the Affordable Care Act in some states is an opportunity to ensure that family caregivers are included in assessments of client needs. And as

Medicaid Managed Long-Term Care plans are introduced, they should be accountable for including attention to family caregiver needs and limitations in developing care plans.

Caregiver organizations as well as palliative care groups can play a major role in educating the public about palliative care – what it is and what it is not. [Professional education](#), as suggested in a previous *Health Affairs* Blog post on palliative care from Charles von Gunten and Betty Ferrell, must address the needs of an aging population with chronic illnesses.

When presented as an option that relieves pain and suffering and that supports the patient and family in achieving the best quality of life possible, palliative care is more likely to be accepted, requested, or even demanded. Palliative care has much to offer people with serious illnesses and their families; it should be readily acceptable, available, and affordable.