Family Caregivers: A Shadow Workforce in the Geriatric Health Care System?

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Abstract  Based on two years of fieldwork, conducted between March 2003 and March 2005 in the health care industry of the northeastern United States, this study shows that the work of family caregivers of elders goes far beyond previously recognized care in the home to acknowledge care inside health care facilities and in conjunction with community services. It reveals that family caregivers—untrained, undersupported, and unseen—constitute a “shadow workforce,” acting as geriatric case managers, medical record keepers, paramedics, and patient advocates to fill dangerous gaps in a system that is uncoordinated, fragmented, bureaucratic, and often depersonalized. Detailed examination of what family caregivers actually do in traversing multiple domains reveals the extent of their contribution to and the weaknesses in the present geriatric health care system. It suggests that the experiences of family caregivers must be central to the creation of new policies and a more coordinated system that uses the complex work of family caregivers by providing the training and support that they need.

Two major socioeconomic trends are changing the terrain of elder care in the United States. First, the population is aging. Current statistics and future projections underscore this point: in 2000, there were 36.3 million
people older than sixty-five, and in 2050, there will be approximately 86.7 million people older than sixty-five (U.S. Census Bureau 2004: tables 2a, 2b; National Alliance for Caregiving and AARP 2004). Second, our fragmented health care system—the geriatric health care system in particular—is under increasing strain. Health care costs are climbing, workforce shortages in key occupations such as nursing are worsening, and the length of time physicians can spend with individual patients is declining.1

Some implications of these trends are clear: the aging of the population means that more elders will need care for longer periods of time, and the strain on the health care system means that many health care institutions have a diminished capacity to respond adequately to the needs of elders. What is not clear, and what this article highlights, is the way in which these trends converge in the lives of families and present family caregivers of elders with significant and sometimes uncharted responsibilities.

We argue that family caregivers play an increasingly critical role in the functioning and the monitoring of the geriatric health care system. By closely documenting what family caregivers do both inside and outside of health care institutions, it is possible to understand the impact of their expanded role on both their daily lives and the daily operation of the geriatric health care system. We further suggest that policy debates about the aging of the population and health care reform require increased attention to the work of family caregivers in order to develop new policies that will be responsive to both economic and quality-of-life issues.

**Current Conception of the Family Caregiver: What Does the Literature Say?**

Over the past twenty years, a substantial literature has developed on unpaid family care work in general and on family caregivers of elders in particular. Academic research, informed by the social sciences and the medical specialties of geriatrics, palliative medicine, and nursing, has produced a geriatric and end-of-life issues. Dr. Robert Buxbaum and Joan Berlin, LICSW, also contributed enormously to this project through their own clinical leadership and personal guidance. Their careful reading of an earlier draft added greatly to the article’s accuracy and analysis.

Finally, we express deep appreciation to the family caregivers who agreed to be interviewed for this research. At a moment of great difficulty in their lives, they gave generously of their time and wisdom.

1. Over the decade from 1993 to 2003, personal health spending rose by 86 percent, and program administration and the net cost of private insurance rose by 125 percent. See Sager and Socolar (2005).
detailed understanding of who family caregivers are and has documented many of the challenges they face.

Feminist analysis has highlighted the gendered nature of family care work and has documented how little the traditional caregiver role has changed, thus posing a challenge to gender equality despite the large number of women who now work outside the home (Tronto 1993; Hooyman and Gonyea 1995; Harrington 1999; Folbre 2001; Garey et al. 2002).

Another line of research on family care has focused specifically on the time squeeze of the employed family caregiver (Googins 1991; Neal et al. 1993; Moen, Robison, and Fields 1994). These studies have documented the difficulty of managing child care and job responsibilities, elder care and job responsibilities, or both kinds of care, as experienced by the famous sandwich generation (Scharlach, Lowe, and Schneider 1991; Merrill 1997; Doty, Jackson, and Crown 1998; Martire and Stephens 2003). Some studies use time diaries to capture and quantify hours spent and resources expended, and these data have provided a more in-depth, if not complete, picture of care work (Bittman et al. 2004). Although child care has received more attention in the past, elder care is gaining increasing attention due to the demographic shifts described above. Studies on elder care have emphasized the need for flexibility — flexible hours, schedules, and location — to manage both jobs and elder care. Research has documented the kinds of policies and services that employers have developed in response, their utilization by employees (Wagner and Hunt 1994; Medjuck, Keefe, and Fancey 1998), and the costs to business (specifically high absenteeism, turnover, and low productivity) of not providing flexibility (Coberly and Hunt 1995). Other studies have examined the costs to the employees in lost wages, disrupted careers, and smaller pensions (Ginn and Arber 1996).

There have also been a number of studies on the negative impact of caregiving on the physical and mental health of individuals providing elder care (Berg-Weger, Rubio, and Tebb 2000; Lee, Walker, and Shoup 2001). This research includes subjects who are employed as well as those who are retired or never worked. Taken together, these studies document high levels of stress, stress-related illnesses, anxiety disorders, and depression (Lechner 1993; Starrels et al. 1997; Navaie-Waliser et al. 2002). Family caregivers are often extremely fatigued, and those lacking respite are at risk of compromising their own well-being to the point of jeopardizing their ability to provide care. Some studies suggest job interventions for supporting employed caregivers (Donaldson 1995). Other studies suggest the need to listen to the voices of caregivers and provide practical support
and guidance. This has resulted in some recent publications and handbooks that center on the stories of individual caregivers and draw lessons from personal experience to ease the stress of caring for elders (Margolies 2004; Kane and West 2005; Harvard Medical School 2004).

The studies by gerontologists and geriatric practitioners—including physicians, nurses, and social workers—are also filled with documentation of the problems that caregivers have and calls for increased support (Levine 2004; Feinberg and Newman 2004). The suggestions for expanded caregiver support range from support-group models (Smith and Toseland 2006), to adult day-respite services (Gitlin et al. 2006; Zarit et al. 1998), to training and skill building (Gitlin et al. 2006). Scholars call variously for responses from personal physicians (Rabow, Hauser, and Adams 2004), nursing home staff (Tornatore and Grant 2004), and community consultants (Teri et al. 2005).

Sociologist Nona Glazer (1993) moves the argument about burdened caregivers from homes into health care institutions, in which she notes an increasing shift of responsibilities for care from paid staff to families and criticizes it as cost saving that cuts staff jobs. However, her interviews were conducted only with hospital workers and administrators, not family caregivers who say, in our interviews, that they want to provide care in hospitals and rehabilitation centers but need more support and training there as well as at home. Recent experiments with physicians making visits to elderly patients in their homes (Korn-Meyer, Toberg, and Boal 2004) and with hospitals creating family-centered geriatric care units designed to increase family involvement (Nichols 2004) point the way toward innovative approaches to broadened support of family caregivers.

A large literature addresses the two key policy questions underlying the care of elders generally: Is the care of an aging population essentially the responsibility of families or government or both? And how can this care be provided in a way that respects what elders and caregivers want and that is affordable for both families and government (Silverstein and Parrott 2001)? The answer to the first question is essentially both, but the second question is still under debate.

There is an emerging consensus that the most cost-effective and humane way to provide care for elders is to minimize institutional care and rely more extensively on community-based home care (Feinberg 2004). However, there is no clear consensus about how large a public investment in institutional or home care is reasonable or what the true costs and benefits of a community-based strategy that relies extensively on the time, skills, and financial resources of families are. To determine the comparative
costs of institutional versus home care, some scholars have undertaken calculations of the value of family care measured in dollars (Arno, Levine, and Memott 1999; Wolf 2004; Netten and Beecham 1993) or estimates of gross household product (Ironmonger 1996). Others warn against under-valuing care work done at home whether by families or paid care workers, propose policies such as compensation for family care and programs for respite care, and call for increases in paid home health services, including increases in the funding and services of Medicare and Medicaid (Stone 2000, 2003).

Another line of research, spearheaded by Carol Levine at the United Hospital fund, broadens the policy discussion by calling for more attention to the details of the work that families actually do and their relationship to health care institutions and home care service organizations. Levine (1998) authored a report on the experiences of caregivers in the health care system that provided a much-needed institutional focus. In the same year, the United Hospital Fund collaborated with several organizations to conduct a national survey to document the full range of caregivers’ work and the relationship of caregivers to the formal medical care system. The survey results highlight the fact that family caregivers are not only involved in the personal care of elders, but they also have “significant involvement in medically related tasks” (Gould 2004).

**A Different Approach: Family Caregivers as a Shadow Workforce**

Our approach extends the requirements for new policy and practice beyond the bounds of current discussions, which do not fully account for the variety and complexity of the caregiving work that families perform or the dependence of the present geriatric health system on family caregivers. We demonstrate in concrete detail that measuring the value of care work at home, while essential, is nonetheless seriously incomplete because it does not capture the full range of work done by family caregivers outside the home in relation to health care institutions and community agencies. We also complicate the policy discussion by casting family caregivers not simply as active outside the home but as essential to the operation of the present health care system for elders.

Specifically, most research still treats family care as something that goes on largely in private homes and households. This is the basis for the commonly made distinction between “formal care” and “informal care” (Folbre and Bittman 2004; Wiles 2003; Ungerson 1995; Walker, Pratt,
and Eddy 1995; Arber and Ginn 1992). In this dichotomy, formal care constitutes care provided in institutions by providers who are trained and paid for what they do, and informal care constitutes care provided outside of institutions by providers who are untrained and unpaid (Bittman et al. 2004). Using a sample of family caregivers who provide elder care, we show explicitly that the distinction does not reflect the reality of what family caregivers do.

We argue that, despite the lack of formal training and monetary compensation, family caregivers actually operate as part of the geriatric health care workforce. Further, we call attention to their role by naming them a “shadow workforce” because the care they provide—especially inside a variety of health care institutions—is largely unseen and unrecognized.

Responding to the call to “better define and measure caregiver activities in order to capture the full range and complexity of caregiver tasks beyond the commonly used ADL-IADL [activities of daily living and instrumental activities of daily living] measures” (Levine and Murray 2004), we show that caregivers move constantly with their elderly relatives—from doctors’ offices to hospitals, to rehabilitation, to home, and often back into hospitals or rehabilitation—and play a significant paramedical role in health care, whether in institutions or private homes. In fact, it is their work in a variety of inpatient and outpatient settings that provides some cohesion among the pieces of an often fragmented geriatric health care system.

We suggest that a more holistic analysis—which links health care institutions, community services, and private homes and sees them as part of a geriatric health care system—is needed to measure the full extent of the personal care, medical care, and geriatric case management that elder caregivers perform. Such an analysis also makes it possible to envision a more coordinated system that utilizes the complex work of family caregivers and provides the supports that they need. Further, recognizing the cross-institutional nature of family caregiving for elders suggests a strategy to gain needed support. If the cross section of stakeholders who interact with families—nonprofit and for-profit health care providers, community-based service organizations, and public-sector agencies—better understood the nature of the work that families do, they might see the benefit of joint action.

Using data obtained from family caregivers of the elderly, this article identifies specific problems within the current system of geriatric health care and areas in which reorganization and increased caregiver support and training are particularly needed. By looking at what families actually do when institutional blocks or disconnects often compromise the
care of elders, we highlight both what families do well to ameliorate such problems and how families could improve their caregiving with better support.

**The Context: A Geriatric Health Care System in Pieces**

The work of family caregivers crosses two primary domains, both of which are marked by territory that is difficult to navigate: one is an uncoordinated, fragmented, bureaucratic, and often depersonalized health care system and the other is a usually underfunded and almost always understaffed community-based service-delivery system. Both systems create significant and sometimes dangerous gaps in the care of elders and require families to assume a large and increasing portion of the care without the resources and training they need.

In the course of treatment for a health issue, elders and their families typically encounter multiple institutions with different systems of organization and communication and dozens of people — clinicians, case managers, administrators, technicians, home health aides, and clerical workers — whose functions are often unclear to patients and their families. The process generally begins with family doctors or primary care physicians (PCPs) who are usually part of a health maintenance organization (HMO) or practice group. At this point, insurance issues may arise. Although all elders sixty-five and over are covered by Medicare, many of the services and procedures they need may be covered only by a supplemental Medigap policy. The same insurance problem also applies to the services of specialists whom patients are likely to see for common afflictions of the elderly — heart disease, cancer, arthritis, bone fractures, diabetes, and dementia. The specialists may or may not be in a group practice with patients’ PCPs, and if not, they often lack easy access to patients’ medical records.

For care beyond doctors’ offices, patients and family caregivers may encounter hospitals, rehabilitation facilities, or nursing homes, all with discrete information systems and in-house nursing and technical staffs, who may or may not have direct contact with referring physicians. In a hospital, patients might remain under the supervision of their PCPs or specialists, but increasingly they are cared for by *hospitalists* — staff physicians employed by the hospital who make daily decisions about care but who have no previous knowledge of or continuing relationship with patients and their families.
When patients go from the hospital to rehabilitation and then home, they return to the care of their PCPs, who usually lack the capacity to coordinate information and care among the institutions that have cared for their patients, and the institutions think their job is done when the patient is discharged. This situation becomes particularly complicated when patients at home require the support of community-based health care services such as visiting nurses, home health aides, medical equipment technicians, or specialized testing or treatment centers. Add to this puzzle of unconnected pieces the fact that all parties are under financial pressure and subject to episodic reorganization, and the challenge facing elders who need health care and community services and the family members who help them is enormous. The current complexity of the family caregiver role has developed in this context of fragmentation and lack of cross-institutional communication.

The Methodology

This article is based on fieldwork in the health care industry in the northeastern United States between March 2003 and March 2005. We began the project by documenting the lives of two dispersed teams of health care clinicians—a geriatric care team and a palliative care team—employed by a large multispecialty practice group. We conducted work observations in a variety of health care facilities and interviewed team members and some spouses about how they managed their daily work lives and family lives. We observed the teams trying—with some difficulty—to coordinate their work across a cumbersome and uncoordinated health care system. While they did, to some extent, follow patients from acute care hospitals to rehabilitation facilities, their contact with patients in these settings was fairly short term because many hospitals and skilled nursing facilities have shortened the length of patient stays to control costs. In some cases of recent multiple hospitalizations, care teams extended contact over a period of months with home visits by a physician or nurse practitioner who provided guidance for family caregivers as well as treatment for patients.

In the course of our observations of team members and their interactions with patients and families, it became apparent to us that family members are the ones who have long-term relationships with these elderly patients and who provide care and continuity in all venues. We then began to study the family role directly. We conducted in-depth interviews with fifty family caregivers whose elderly relatives had been patients in the prior year in
Due to HIPAA regulations and the terms of the institutional review board approval we received from the health maintenance organization, we were not allowed to interview any of the patients. Some caregivers responded by sending back a form, while others responded through follow-up telephone calls. Given this method of contact, our sample is self-selected and probably does not include families who are less involved in direct care. We conducted semistructured interviews: the majority were conducted in caregivers’ homes and taped, while some were conducted on the telephone. The same interview protocol was used in both situations.

Within our sample, most interviewees were still active caregivers at the time of the interview, although a small group had recently lost the person for whom they provided care. Not surprisingly, given the gendered nature of family care work, two-thirds of the caregivers were women. Also not surprisingly, given that the life expectancy of women is longer than that of men, most of those cared for were female relatives, usually mothers of caregivers. The caregivers ranged in age from their early forties to their late eighties, with the majority (70 percent) in their forties and fifties. One-half of the group was employed on either a full-time or a part-time basis, one-third was retired, and a little over one-tenth had left the workforce temporarily to accommodate their elder care responsibilities. Over one-half of the group had at least some college education, and one-quarter had a graduate degree.

Overall, the sample was economically and racially diverse; roughly one-quarter of the sample was eligible for publicly subsidized support services, one-tenth had household incomes over $200,000, and the majority had incomes ranging from $30,000 to $100,000. One-tenth of the care-
givers lived outside of Massachusetts and traveled frequently to care for an elderly relative in the state. Most of the caregivers we spoke with were born in the United States, although a few were immigrants from Europe or the Caribbean. Nearly one-third of the sample was African American, and a few respondents were Hispanic.

The profile of this group of family caregivers is fairly close to the national profile of family members caring for individuals over the age of sixty-five, so we feel reasonably confident that the experiences of the caregivers we met reflect the experiences of many others involved in caring for elders (see table 1).

### The Institutional Disconnects: A Close Look

We arrived at 124 Perry Street in a working-class neighborhood of Boston to interview Robert O’Malley. He lived on the second floor of a two-family home, and his two adult sons also resided there. He introduced us to his wife, Margaret, and their home health aide, Beatrice. We sat at the dining-room table; Robert sat in his wheelchair, as he was still recovering from a stroke. Margaret sat in her wheelchair in the living room watching a daytime television show; she was recovering from hip replacement surgery. Between them, they dealt with seven chronic health conditions. Robert explained that Margaret did not really like television, but she could not read or crochet—her two favorite pastimes—because she had been unable to see her ophthalmologist for a new prescription for her glasses.

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**Table 1  Family Caregiver Demographics**

<table>
<thead>
<tr>
<th>Our Sample (N = 50)</th>
<th>National Profile</th>
</tr>
</thead>
<tbody>
<tr>
<td>66% women</td>
<td>63% women</td>
</tr>
<tr>
<td>70% 40–59 years old</td>
<td>65% 35–64 years old (mean = 47 years old)</td>
</tr>
<tr>
<td>65% earn $30K–$100K</td>
<td>52% earn $30K–$100K</td>
</tr>
<tr>
<td>34% minorities, mainly African American</td>
<td>American (11% of the 25%)</td>
</tr>
<tr>
<td>50% employed, either part time or full time</td>
<td>57% employed, either part time or full time</td>
</tr>
<tr>
<td>Over 50% have at least some college</td>
<td>67% have at least some college</td>
</tr>
</tbody>
</table>

*Source: A national survey of 1,247 family caregivers conducted in fall 2003 (National Alliance for Caregiving and AARP 2004)*
Margaret was frustrated, and Robert felt powerless in a system in which the pieces did not fit together and each piece was governed by rules that made no sense.

Robert explained that Margaret was able to get from their second-floor apartment down to the first floor—Beatrice moved her from the wheelchair to the electric chairlift. Margaret was also able to get from the sidewalk in front of their house to the wheelchair van—the men who worked for The Ride could do that. But there was no one and no agency authorized to get her from the inside front hall of her house, down the outside porch steps, and into the wheelchair for the van. The home health agency forbade Beatrice from touching Margaret outside of the house. The Ride forbids their drivers to go inside the houses of their van riders. In Robert’s words, “I can get her down to the bottom but there’s no way to get her out in the wheelchair . . . somebody has to get us out, down off to the [porch] stairs so that she can be picked up . . . the wheelchair men come and get her but they will not touch her beyond the stairs.”

Mr. O’Malley’s story was one of many we heard from family caregivers about a pervasive lack of coordination and fragmentation in the geriatric health care system. In this instance, there was no coordination between a professional health care provider—Margaret’s eye doctor—a home health care agency, and a community transportation service, all of which were needed to get Margaret new eyeglasses. There was literally a missing link in the system—a physical space Margaret could not cross—because the health care provider and the community services on which Robert and Margaret relied were not being coordinated.

Family caregivers reported lack of coordination within health care institutions as well as between institutions. Within hospitals, for example, family caregivers said that doctors often do not talk to each other about patients they have in common, and a few said that they did not see the same doctor twice when their relatives were hospitalized. One caregiver came from Texas to care for her elderly mother after knee replacement surgery. She explained that her mother had a preexisting heart condition, but her mother’s cardiologist never spoke to the orthopedic surgeon before the operation, and after the operation they put her mother in a surgical unit without specialized heart-monitoring equipment. This lack of coordination compromised the quality of her mother’s care and could have jeopardized her mother’s life.

Family caregivers also experience this lack of coordination in the constant transitions that elders experience from hospital to rehabilitation to home. Although most transfers from hospitals to rehabilitation facilities
go smoothly, this is not the case when a transfer occurs over the weekend. Lillian Smith, who frequently traveled to Boston from Chicago to care for her mother and stepfather, described what happened when her mother was transferred to a rehabilitation facility on a Saturday: the receptionist did not have her mother’s name when she arrived by ambulance, and details of her medications and dietary requirements did not reach the skilled nursing facility until Monday.

The most prevalent difficulties seemed to occur in the transition from rehabilitation to home. In some cases, the patient was discharged prematurely. Most rehabilitation facilities require that patients have a certain level of activities of daily living (ADLs) and physical mobility and that each patient’s home has been inspected for handicapped access and safety. A number of caregivers reported that homes were not checked before the discharge, patients’ ADLs and mobility were not good enough for them to be home, or home services that were available were far less than those promised, burdening the family with almost full responsibility for around-the-clock care. Such situations — reported by three caregivers we interviewed — can result in unnecessary falls once the patient gets home, which may lead to rehospitalization or more time in rehabilitation. In other cases, the transition from rehabilitation to home was too slow. One woman whose mother was dying of pancreatic cancer kept trying to get the rehabilitation facility to discharge her mother who longed to be at home, but the rehabilitation staff delayed the move without making their reasons clear to the distressed family.

Home Care Services: The Disconnect at the Community Level

The biggest problems with lack of coordination occur when family caregivers are involved in home care and are highly reliant on a variety of community services, especially if they are employed. Each service must be set up and then monitored over time. There are state agencies that offer multiple services — Aging Service Access Points or Area Agencies on Aging — but many caregivers do not know these agencies exist or where to find one near them. More often than not, family caregivers have to call separate places for home health aides, housecleaning, transportation, food services, prescription drugs, and specialized medical equipment and supplies. They must also make judgments at each step about the appropriateness and quality of services and, in many cases, about medications and unfamiliar medical items that they must acquire.
At each of the transition points described, there is a need for geriatric case management to insure that all the patient care and information is coordinated, but many family caregivers said they had access to a case manager who could do this only at the moment of hospital or rehabilitation discharge. Most caregivers reported that, once home, they had no one to help them access, coordinate, and monitor services over time. At least one reason is economic. Social workers and case managers are available at public agencies but only to families with very low annual incomes, and private agencies that provide such services charge fees affordable only to families with very high annual incomes.

Chuck Regan, a Boston police officer with a stable middle-class income, explained how the lack of access to a case manager affected him. He rarely received calls from his mother’s PCP or her oncologist, and the doctors did not talk to each other, as best he could tell. He had no one to help with his mother’s shopping and other errands, and he did not know where to get her a better walker. With no one to coordinate his mother’s doctors and the services she needed, Chuck spent his days—the time from noon until seven o’clock in the evening when he was not sleeping or working third shift—calling doctors, taking his mother shopping, picking up her medications, and calling around to find out where to get a new walker. The home health aide who had been coming into his mother’s apartment a few hours a week had recently quit, so he had to add finding a new aide to his “to do” list.

This lack of coordination at the community level results in constant demands on family caregivers and their elders. Many family caregivers complained about the stress involved in calling and monitoring multiple services, the difficulty of finding a reliable person to help and then losing them, and the frustration of communicating with multiple community agencies.

For example, one caregiver, Rhonda Simon, whose mother had a degenerative disease and was confined to a wheelchair, tried to get her mother moved from a regular apartment in a subsidized elderly housing project to a handicapped-accessible apartment in the same project. This process involved gathering documentation and letters from two of her mother’s doctors and attending and testifying at a hearing. After her mother’s request was finally approved, Rhonda was told that there was no apartment available, and her mother was put on a waiting list with no clear end date identified. Rhonda was eventually contacted by the public housing authority and was told that they had a handicapped-accessible apartment, but it did not have the roll-in shower she originally requested. The bath-
room that was available would require Rhonda’s mother to do a bench
transfer to get into the shower, and this change required more doctors’
letters, another hearing, and another waiting list. At no point was there
any direct communication between her mother’s doctors and the housing
authority, reflecting an overall lack of communication between health care
institutions and public agencies.

These pressures and frustrations inevitably take a toll on the employ-
ability, as well as the physical and mental health, of caregivers. For exam-
ple, Rhonda was put on medication for depression and anxiety to help her
cope with the pressures of caregiving. Chuck found it difficult to sleep in
between his third-shift job and his afternoon elder care responsibilities.
Lillian had to make so many trips between Chicago and Boston that she
temporarily dropped out of the workforce until she could find a job with
sufficient flexibility.

**Information Searches, Communication Barriers**

Troubles for the family caregiver stemming from lack of coordination
among health care institutions — and between health care providers and
community services — are greatly exacerbated by the difficulty of locating
needed information and receiving it when needed. This includes both
medical information and information about the services and resources
available in their community for home care.

**Medical Information**

Difficulties obtaining medical information usually begin in the doctor’s
office or in a hospital. Doctors need several kinds of information from a
patient. They need to know how the person is feeling physically, including
the extent of pain and other symptoms. In a first visit they need a
patient’s medical history. Whether or not physicians have prior knowledge
of a patient, they also need information about current medications. Elderly
patients are sometimes able to answer such questions themselves, but often
they are not — either because of memory loss or other difficulties related to
illness. In these situations, the family caregiver is critical, often describing
the trajectory of a patient’s condition and providing detailed information on
the patient’s history and medications. Some caregivers we spoke to told us
they often knew about allergies to medications and preexisting conditions
that were not listed on patients’ charts or electronic medical records.
When clinicians lack specific information on patients’ medical histories, they may revert to standard protocols, sometimes with adverse consequences. In one instance we heard about, the use of a standard procedure may have resulted in the death of a woman with advanced Alzheimer’s disease who was in rehabilitation after surgery for a broken hip. She had received multiple new medications to which she reacted badly. When she developed trouble breathing, she was sent by ambulance to a nearby hospital but died on the way. Her daughter said that in the preceding few days everyone caring for her mother seemed to be doing the right thing in response to particular symptoms, but no one who knew the patient’s history seemed to be in charge of the overall situation.

Dr. M. . . . was supposedly seeing her but I don’t know — we never saw his records. It was always somebody else. I mean, everybody cared and was really nice and she was never mistreated but there just didn’t seem to be any. . . . there was no big picture of anything. Everybody had their own little domain. . . . I think she just fell through the cracks in terms of being monitored.

As physicians need information, so do patients and family caregivers. Depending on the situation, necessary information could include an explanation about what tests are needed, a diagnosis, a fully described treatment plan or set of treatment options, and the physician’s prognosis. Caregivers report a number of difficulties getting this information in a clear and timely way.

When caregivers do hear reliable information from a known person, helpful providers appear by name in their stories. Laura, whose husband has had multiple brain surgeries, gratefully named the people who took the trouble to provide her with precise information when she needed it. In the course of the interview, she named a friend, a neurosurgeon, his executive nurse, and his junior assistant. She was particularly grateful to the junior physician who put scans on a screen and showed her in black and white that fluid was no longer building up and pressing on her husband’s brain. This concrete information was critically reassuring at a time of high anxiety and stress.

When caregivers have difficulty tracking down information about what is wrong or what the expected trajectory of an illness is — what to expect and how to prepare — increasingly they turn to the Internet for information. They become avid researchers, but when, without medical knowledge, they cannot evaluate what they find, this is also frustrating.
Home Care Information

When an elder is discharged from a hospital or rehabilitation facility and caregivers are faced with the challenges of organizing home care, they may need simple factual information but spend hours trying to find it, often blocked by complex routing systems for inquiries that vary in different institutions.

The Folder

If caregivers have not had previous experience with home care services, do not know the reputation of various companies for quality and reliability, or are not even very clearly sure what particular services the patient will require, they need guidance. Caregivers need highly specific information, but prior to that, they need to know what information is needed. They may receive helpful advice from a social worker or case manager in a discharge meeting, but many report that mainly what they receive is “the folder.” This is a collection of brochures from home care organizations and companies offering nursing service, personal care, general support, medical equipment, dietary supplies, and so forth—a massive amount of information. However, the information is undigested, bureaucratized, and impersonal—essentially marketing material that paints a vague and rosy picture of the service or agency in question. What caregivers need is help assessing these agencies and services so that decisions and choices can be made on an informed basis. Discharge nurses or social workers do not usually provide assessments and recommendations due to the potential liability of the hospital or rehabilitation facility if a recommended service or piece of equipment is faulty. For caregivers, the result is a decision-making process that is risky, difficult, and perhaps influenced by a mistaken impression that the institutions providing the folder implicitly approve the material they hand out.

Automated Telephone Systems

Once the patient is home—and the family caregiver is left virtually alone to know everything and do everything—the caregiver’s sense of frustration and isolation is exacerbated by the ubiquitous automated telephone system. Laura, who cared for her diabetic husband, depended on access to information about how to handle his potential for seizures. She said, “I don’t like telephones where you have to press buttons, hold, put you on
hold, and put you on a tune, and then, you know what they do, you have
to press buttons . . . but I have to deal with that. I have to deal with his
medication.” Living in housing for the low-income elderly, the couple had
substantial home care services, but the complexities of their medical con-
ditions produced continual questions and the need for information from
multiple clinicians. Laura managed this demanding process, but like many
caregivers, she did it by fighting her way through a telephone maze and
paying a considerable cost in aggravation, stress, and time.

Of course, automated telephone systems replace human purveyors of
information and allow health care organizations operating under financial
pressures to function with smaller staffs, but when such practices reduce
vital information for home care by family caregivers, the financial sav-
ings are questionable. For example, after staff cuts in a dialysis center, a
family caregiver stopped getting reports on her husband’s weight and new
recommendations for his strictly controlled diet. Alice said, “I don’t get
any information unless I call and most of the time the social worker is not
there so they will have to leave a message for whichever day she is com-
ing in, or whatever. But it is not like two years ago—it was really good.”
This loss of information created difficulties for Alice, as she worked full
time as a certified nurse’s aide in a nursing home and, without guidance
about her husband’s changing dietary needs, she had to “think everyday”
about what food to fix for him—“which is very hard.” Shortly before we
arrived, she had reduced her work hours from full time to part time.

Anticipating Needs

Another deep frustration for caregivers is the difficulty of finding informa-
tion about anticipated needs. This is a common concern for adult children
taking care of parents who are in fairly good health but who face a decline
that will require some form of institutional support. Judy, a school admin-
istrator, had begun to think about what to do when her mother would
need more care and, in spite of familiarity with research tools, she did
not know where to go to find usefully organized information. She went
online to look for adult day care in her area and could not find a helpful
Web site or anything coherent. All that turned up was a high-tech version
of the folder.

Some family caregivers spoke of the need to understand the trajec-
tory of their elderly relatives’ illness in order to prepare both logistically
and emotionally. As Rosalind, whose mother had advanced Alzheimer’s,
told us, “We need steps . . . No one explained to me that eventually my
mother’s going to end up like a vegetable with a tube, and that’s probably how she is going to pass away . . . So, you know, I’m all like with my hopes up . . . like my mother’s not going to leave home.”

In this story and others, medical and care issues are intertwined, and family caregivers need timely information, both to prepare for the future and to allay the stress of imagining what the progression of the disease will be. In general, caregivers suffer a frustrating imbalance between significant responsibility for someone’s health and lack of information and control over the conditions for maintaining it.

**Gaps in the Health Care System for Elders**

As family caregivers of elders deal with the fragmentation of health care institutions and the difficulty of accessing information, they confront a lack of needed services that they then seek to provide themselves.

**Understaffing, Turnover, and Patient-Provider Mismatch**

Caregivers reported significant understaffing in hospitals, particularly on the weekends and during major holidays. This could lead to medicines and diet not being carefully monitored, call buttons going unanswered for both medical and nonmedical needs, and even some instances of neglect resulting in the exacerbation of an existing condition.

In rehabilitation or skilled nursing facilities, inadequate staffing levels led to caregiver reports of bedsores, patients being left in the hallways without programmed activities and other opportunities to socialize, and other complaints related to personal care, particularly toileting. In one instance, a woman fell out of her bed and broke the leg that had just been operated on, and in another, a woman developed a urinary tract infection that the staff was slow to treat with antibiotics.

Staffing problems also surface once a patient returns home. The major family caregiver complaint about home care services is the significant turnover among aides. Although a number of family caregivers seemed sympathetic to the challenges facing aides doing difficult and important work at very low wages, they nonetheless reported problems with aides who came late, were absent, and did some tasks begrudgingly — and problems with agencies that sent aides clearly unsuited to particular patients.

One woman, herself a health care professional, was greatly frustrated with the agency providing home aides for her mother following reha-
bilitation for a hip fracture. The agency was supposed to evaluate the patient’s needs in order to assign an appropriate care worker, but on the first day, they sent an art student on her first job who had no idea what to do. The second person sent was twenty-one years old and tiny — unable to handle the physical demands of helping a rather large woman walking unsteadily.

Another source of tension between patients and aides can arise from differences in language, culture, and race. Many low-paid aides are recent immigrants, including an unusually large number from Haiti, and misunderstanding, mistrust, or outright racism can badly compromise the caregiving relationship. One white woman in a nursing home we saw crying inconsolably finally explained that she did not want her body washed by a black woman.

These myriad difficulties make many caregivers feel that they always have to be present to monitor what is being done — and what is not being done — by nurses and aides, whether at the hospital, a rehabilitation facility, or home. When they feel that the care is not adequate and that their relative is unsafe or unhappy, many caregivers take on additional care tasks that they had been hoping to delegate, resulting in considerable stress and fatigue.

Lack of Geriatric and Palliative Care Training

Family caregivers are very fortunate if their elderly relative’s physicians have received training in geriatric and end-of-life care and have experience with the ailments from which elders most commonly suffer. It is perhaps even more important to caregivers if the doctors with whom they deal are trained to handle the frightening, sometimes devastating issues facing seriously ill elderly patients and their families, especially at the end of life. The important skills range from prescribing appropriate medications for managing pain to delivering information about a prognosis in a way that is both honest and sensitive to a family’s concerns. In some stories, these communication issues seemed at times to override issues of diagnosis and treatment, and the experiences that caregivers reported ran the gamut of emotional interactions.

In one rehabilitation facility, we heard the story of a physician who had been abrupt and insensitive in telling a family caregiver that her husband had an inoperable, fatal cancer, all the while standing in a hallway and checking her watch to be sure she was not late for her next meeting. “Every time I talked with someone that day,” the caregiver said, “I was
standing in a hall. No one ever sat down with me.” To this woman, the lack of privacy compounded with the lack of time to deliver such life-altering news was almost unbearable.

In another facility, we heard about a physician who sat down and talked to the family about the end-of-life decisions that lay ahead. He also went with them to inform the patient that there was no cure but that pain could be minimized and that every effort could be made to provide comfort. The daughter of the patient involved said, “You know he’s a great guy; he’s a very gentle guy and conveys a great deal of caring.”

In both stories, the family caregiver and the patient received stunning news, but the way the news was delivered made a qualitative difference in the ability of the family caregiver to talk with an elderly relative about the difficult issues at the end of life. Not surprisingly, the second physician had specialized training in geriatric and palliative care and years of clinical experience working with elderly patients, while the first physician was a surgical specialist who, to the best of our knowledge, had no geriatric or end-of-life training.

Community Services: Low Quality

Family caregivers also voiced complaints about the quality of various publicly funded community services on which they relied for food and transportation. Both Meals on Wheels and The Ride received almost universally negative assessments in terms of the quality of the service. One caregiver, an adult daughter who could not lift her very overweight mother, had to use The Ride to get her mother to doctor’s appointments. However, she said that the service was highly unreliable, made her mother late for appointments, kept her waiting many hours after appointments, and occasionally did not come at all. Family caregivers often commented that the food delivered by Meals on Wheels was neither hot nor nutritious. One reported that Meals on Wheels was not equipped to meet her mother’s daily nutritional needs and special diet.

The ability of elders to eat well when they cannot cook and the ability to have mobility outside their homes when they cannot walk or drive are basic needs that must be met in community-based elder care. The caregivers we interviewed found these services to be underresourced and understaffed, threatening the ability of families to keep their elderly relatives in their homes.
The Caregiver Response

The issues highlighted—lack of coordination, lack of information, and significant gaps in the provision of health care and community services for elders—have produced a seriously flawed system of geriatric care. These deficiencies often shortchange elderly patients and place great—but unrecognized and unsupported—responsibility on the family caregiver. One important source for improvement in the geriatric health care system, therefore, is a new and broadened understanding of the complex caregiver role—as it is now and as it could be with changes in both institutions and attitudes. The first step is to examine closely what family caregivers are actually doing.

As noted earlier, many studies of family caregivers report on the difficulties involved in caring for an elder, and while all these problems are well documented, together they present only a one-sided portrait—family caregivers as victims. Our data confirm the findings of previous research that document work-family conflict, economic hardship, and negative health impacts. However, we also establish family caregivers as people of agency and action who—seeing the deficiencies of the current health care system up close—step into the breach and become part of a shadow workforce.

The caregivers we spoke to often took matters into their own hands—they played many roles and provided many kinds of care that were essential to the well-being of the elders for whom they cared. We focus on two roles in particular: the family caregiver as unofficial geriatric case manager, a response to the lack of coordination in the system, and the family caregiver as walking medical record, a response to the lack of cross-institutional systems for transferring the medical histories of elderly patients. In addition, we document how some family caregivers act as patient advocates and paramedics to address problems with poor-quality health care and how they construct their own family and community support systems to address the lack of specific supports for their work.

Most important, caregivers do not simply respond to the personal care needs of the elders for whom they care—a view that takes family caregiving out of the multiple contexts in which it occurs. Our analysis places the family caregiver in all domains of a geriatric-care system that includes health care institutions, community-based service agencies, and private homes. It shows that the way the system is currently organized—and the way work is organized within and between health care institutions—directly shapes what it is that family members do. Caregivers are
continually called upon to fill the institutional needs of the system not just the personal needs of an individual elder.

Becoming a Geriatric Case Manager

“There is no one person who knows everything.” These are the words of the woman whose mother died suddenly and unexpectedly in rehabilitation after surgery. The daughter did not allege wrongdoing but bemoaned the simple fact that of all the people involved in her mother’s care there was no one—except herself—who knew all the medical, emotional, and logistical pieces of her mother’s care. The fragmentation and lack of coordination of the current health care system has been described, but family caregivers do not simply accept that as a given. Some caregivers personally become the glue that holds the pieces together.

The family caregivers we spoke to did not use the term “geriatric case manager” to describe their role, but their interviews were filled with the details of such activity. First of all, they managed relationships among medical doctors and between these doctors and other health care professionals. One of the realities of aging is that the body experiences multiple breakdowns simultaneously. One of the realities of the way medicine is practiced today is that many doctors are specialists. Taken together, these two facts mean that any one family caregiver may deal with multiple doctors simultaneously. The caregivers we spoke to dealt with, on average, four doctors at a time; a few reported dealing with between five and eight doctors at a time. There is the elder’s PCP, who is supposed to play a coordinating role but often does not. A referral from the PCP is needed in order to see a specialist—and many telephone calls from the caregiver may be required to secure this referral. Often the PCPs do not put the findings of one specialist together with the findings of another specialist to make a diagnosis or define a treatment plan. So it often falls to family caregivers to suggest to physicians that they need to consult with other physicians.

Rhonda Simon’s story is fairly typical for family caregivers dealing with an open-ended long-term care situation. Her mother suffered from multiple chronic illnesses, so Rhonda had to stay in touch with her mother’s PCP, cardiologist, ophthalmologist, orthopedist, orthopedic surgeon, and psychologist. Dealing with each specialist involved a discrete set of doctor’s appointments that had to be scheduled, follow-ups at different intervals that had to be tracked, and prescriptions that had to be obtained, filled, and refilled—in all, a very time-consuming set of tasks.
And such a set of tasks only involves the medical pieces of the puzzle. For elders who are being cared for at home, family caregivers must be in contact with home health agencies to arrange for aides to assist with personal care and sometimes separate agencies to do housecleaning. There is often a need for visiting nurses, physical therapists, or occupational therapists, and this involves calls to one or more other agencies. In addition, family caregivers must find reliable medical equipment companies for walkers, wheelchairs, IV poles, bandages, commodes, and safety devices. Caregivers may also access help through publicly funded services, such as The Ride, Meals on Wheels, and the Housing Authority — three more agencies, three more sets of calls.

It is not just the calls, however. Geriatric case management is about building and maintaining relationships, and relationships may go well or badly. The key players may be constant, but more often they change. A number of caregivers were frustrated by the turnover in home health aides, not just because they needed to find a new person, but because they needed to share once again a great deal of information about diet, medications, and personal habits and to establish trust with yet another stranger. One of the caregivers told us that she did not mind if the home health aide who cared for her father was late, as long as she came. In fact, she went out of her way to be flexible about the start time for her aide — a mother with young children dealing with her own work-family issues — as a strategy to keep this aide in her employ and minimize turnover. This family caregiver combined case-management skills with human-resource strategies.

A Walking Medical Record: Family Knowledge Is Key to Quality Care

Managing medical information is a huge challenge with which many health care institutions grapple. The paper medical record is slowly being replaced by the electronic medical record, but this process is uneven at best. Even if one institution that a patient uses has computerized its medical records, the information may not be easily transferable to another health care institution caring for the same patient if the institution’s records are not yet computerized or use an incompatible computer system. Caregivers reported that the privacy regulations of the Health Insurance Portability and Accountability Act (HIPAA) created additional impediments to creating a cross-institutional medical record. This means that the information that a hospital-based doctor or nurse has may or may not reflect the latest exam by the patient’s PCP or the latest test results ordered by a specialist.
However, patients who are sick today cannot wait for the national electronic medical record system of the future. Enter family caregivers.

Family caregivers reported that they were often the ones able to supply key pieces of medical information in a timely manner. When elderly patients are examined by physicians whom they have not seen before, they are often asked what medications they are on, and it is commonly family caregivers who can name the complete list. Family members are often aware of medication or food allergies that are not in the medical record, and they are able to prevent adverse reactions by sharing that information with doctors. Their knowledge base is especially critical with dementia and Alzheimer’s patients, who literally cannot remember what medications they take, or with those in early stages of dementia, who give convincing but faulty answers. Even for patients with no loss of cognitive function, it is difficult to remember all of the information about diagnosis, treatment, and test results that their doctors may need, and caregivers’ knowledge is often needed to create a more holistic picture of patients’ medical histories.

Family caregivers often have a better understanding of what patients look like when they are healthy than doctors who meet them for the first time when they are sick. One caregiver told us that it was only after she brought certain information about her mother’s appearance and breathing to the attention of the nurse during her mother’s recent hospitalization that a diagnosis of a heart attack was made. Another caregiver repeatedly reported to the hospital nurses that her mother’s left eye drooped after surgery. The staff did not think it was anything, but the daughter knew what her mother’s eyes looked like normally, and eventually a diagnosis of Horner’s syndrome was made.

Some family caregivers showed a high degree of ingenuity in creating systems for managing all the medical information they had compiled. In our interview with Lillian Smith from Chicago, she described her system of logbooks and files. Her parents were in Boston, and being a long-distance caregiver added to the challenge of Lillian’s information management. She was responsible for her mother and her stepfather, both of whom dealt with multiple chronic illnesses. She had created files for each of them: one sheet had names and telephone numbers of doctors, one had names and telephone numbers of community health services, and one had lists of medications. Then she created logbooks for tracking medical information on a day-by-day basis. For example, her mother was diabetic, so there was one page for tracking her blood sugar and another for tracking her weight—information the doctor would need to adjust her medi-
cations. She proudly told us that her mother took the logbook when she went to visit her PCP. This information also became critical in emergency situations. Lillian explained,

I have an information sheet with all the doctors, card numbers, the meds, everything . . . It’s all in one place. I have done that for my stepfather and for my mother now, so that they have sheets, because with my stepdad a lot of times he is going to the hospital in an ambulance at night, you know, he gets nauseous and he wants to go right to the hospital, so I did these sheets up and I have left them there so that somebody coming in can look and say, “Okay, this is what he takes.”

One wonders what happens to the elderly patients who do not have files and logbooks on which to rely or family caregivers who remember to leave information out in a visible place in case of an emergency.

Paramedic and Patient Advocate: Filling Gaps, Stepping into the Breach

The role of family caregivers as members of the geriatric health care workforce is apparent in hospitals, rehabilitation facilities, and long-term care facilities, and at times family caregivers take on specific staff functions, often performing procedures for which nurses receive prolonged skilled training. In hospitals, caregivers monitor medications and diet; tell the doctor what the patient is feeling if the patient cannot; and collect information on diagnosis, medications, and follow-up care. In skilled nursing facilities, given the high number of patients for each staff member, families do everything from going to get help when a call button is not answered, to cooking and bringing in food when a patient refuses to eat the institutional food, to assisting with personal care when staff are not available, to collecting information for the transition home.

Although often unrecognized, the role of family caregivers at home usually includes a significant amount of medical care, along with personal care. Caregivers dress and monitor open wounds, checking for signs of infection; start and monitor IV pumps; dispense medications at the right time of day and in the right dosage; check vital signs; and monitor blood sugar levels, weight, and dietary requirements, especially for elders with diabetes, kidney failure, and heart disease.

One woman who cared for her husband on dialysis noticed unusual chest sounds while he was sleeping and smelled blood on his breath. When she called the doctor, he directed her to watch her husband until
morning. Unsatisfied with that response, she told the doctor, “How can I watch this man just lying here lifeless until morning? I am taking him in whether or not I get your approval.” She had to get her son to drive her husband to the hospital, and once there, the staff gave him painkillers. It was only because of her persistent urging that there was something wrong that doctors eventually took X-rays and upon seeing the results rushed her husband into surgery.

Family members serve as quality-control experts when they monitor the health care that their elderly relatives receive and as patient advocates when quality is lacking. Caregivers reported that they had to intervene when antibiotics to treat an infection were delayed, pain medication was started too slowly, or morphine was not being given at the dosage level that the doctor had prescribed for a dying patient. In each of these instances, the family caregiver had to ask repeatedly for the medication that was needed. The patient advocate role is also important in the transition from rehabilitation to home. One man, a priest by vocation, explained how the discharge meeting for his father was poorly handled. The father was mentally competent, so the staff spoke to him alone. Being of a generation that puts doctors on a pedestal, the father accepted an unworkable home care arrangement. It was not until the son got involved and advocated for a full range of home care services that a suitable and safe arrangement was made.

Once patients are no longer in hospitals or rehabilitation facilities, family caregivers are needed to accompany them to follow-up appointments and often are needed to act as advocates in that setting. Caregivers reported that they often asked questions that the patient had not raised, asked for additional tests, or requested second opinions. The patients themselves were often too overwhelmed by a large amount of new information and the emotional stress of their illnesses. Family members reported that, while they were emotionally involved, they could also take notes and present information to the elderly patient after an appointment.

Creating Caregiver Support Systems

The ingenuity, determination, and acquired skill of family caregivers goes a long way toward providing needed care for elders, but in its present state, health care practice leaves too great a caregiving role to families, at too great a cost—in terms of both the quality of care for patients and the well-being of caregivers. Families want to take care of their elderly members as they have traditionally done, but with systems that measure physi-
cian contact in minutes, that discharge patients from hospitals a minimal time after surgery, and that supply only short-term community services, demands on families have increased exponentially.

While many health care institutions are committed in their mission statements to patient- and family-centered care, this does not usually translate into specific support for family caregivers. These institutions depend on family members, but the system neither recognizes the full extent of their role nor offers a formal assessment of the needs of caregivers or a mechanism for responding to those needs. The needs of caregivers vary, depending on their own age, health status, and the emotional and physical health of the elders for whom they care. The types of support caregivers need also vary.

In some cases, caregivers need the kind of social and emotional assistance available through support groups. Support groups enable caregivers to learn from the knowledge and experience of others, lessen their sense of isolation, and voice their concerns to others who truly understand their situation. They can also get information and access to resources they may need, such as respite care, and the encouragement to use supports for themselves. It is striking that very few caregivers we interviewed — only three, in fact — had access to support groups or respite programs. One woman caring for her husband with advanced Alzheimer’s belonged to a caregiver support group through her town’s Council on Aging, but there were few other examples.

Given the scarcity of caregiver support programs provided by institutions in the geriatric health care system, we found that family caregivers took the situation into their own hands and constructed their own support systems. Sometimes they organized help for practical tasks, such as transportation to doctors’ appointments, and sometimes they sought emotional support. The most common support systems included extended family members, usually adult children relying on their siblings in caring for an elderly parent or adult children relying on their own adult children for help with this care. We found a number of examples of caregivers living in two- or three-family homes with an elderly parent and sometimes other relatives as well. For example, Angela Thompson, a retired aerospace worker, owned a three-family house. She and her eighty-five-year-old mother lived on the second floor, her brother lived on the third floor, and her cousin lived on the first floor, so she had relatives nearby to help her with her mother’s care. When one sibling lives locally and the other lives out of state, some families devise a way of sharing the caregiving so that the person living locally is not the sole person responsible for caregiving.
Of course, not all families are able to share elder care effectively. In some cases, a caregiver is an only child; in other families, there is a history of difficult relationships and/or illness that militates against shared care, and this can become an additional source of stress for the family caregiver. About one-quarter of the sample did not have an extended family support system, and in these cases long-term home care was not sustainable. One caregiver managed to keep her mother in her own home for seven years, but her siblings refused to help with their mother’s care. Eventually the toll of being a single parent, a full-time nursing home worker, and an elder care provider caught up with her, and she sadly moved her mother into a nursing home.

Some caregivers actively draw on individuals and resources beyond their own families. A number of caregivers reported support from their religious congregations. One elderly woman who cared for her husband could no longer drive, so her minister frequently drove her to the grocery store and to doctors’ appointments. Another woman was able to find a couple to provide live-in help with her husband through a friend at her church. Jean Baptiste, an immigrant from the West Indies who took early retirement to care for his wife, was very active in his church and told us that he had not yet called on his fellow congregants, although several had visited. He was waiting until his wife—a stroke victim—became more needy to enlist their help, showing that family caregivers can be quite strategic in their use of community support and resources.

A small group of caregivers mentioned friends and/or neighbors on whom they relied for support. Neighbors seemed to provide logistical support, shoveling walks in winter, putting out garbage, or picking up prescriptions, while friends often provided emotional support, talking on the telephone and listening to the trials and frustrations of being a caregiver. Among caregivers who were elders themselves (28 percent in this sample), many said that their contemporaries had so many health problems of their own that they were reluctant to talk about their problems or ask for any form of support.

In sum, family caregivers did not wait for health care organizations or community-based agencies to provide support. They turned to family and to those with whom they live, pray, and socialize to create a support system that could help them on a practical level and give them the emotional strength to be involved in long-term elder caregiving. However, it is important not to confuse what caregivers themselves are able to organize with the desirability of a multipronged approach to caregiver support organized by health care institutions and home care service organizations.
Discussion: How the Family Caregiver Experience Can Inform Policy Directions

Family caregivers play an unnamed but critical role in the geriatric health care system. Our data show that they operate as a shadow workforce; they are in the shadows because their work is not seen as such, both literally and in terms of recognizing the breadth and depth of their activities. In discussing elder care, the distinction that is frequently made between formal care and informal care obscures the real nature of what family caregivers do in two ways: first, they do work in formal institutions, not just in private homes; second, their work combines personal care, medical care, and infrastructure support. Furthermore, family caregivers provide cross-institutional links among formal health care institutions and between health care and community institutions. In a system that lacks both coordinated care and information, family caregivers perform important integrative functions, add significant value to the quality of care, and help to reduce the costs of health care.

The current impact of family caregivers on families and on the health care system is contradictory. The term “family caregiver” itself, combining “family” and “caregiver,” evokes instant approval. Providing care is a good in itself. Caregiving is an act that satisfies a human desire for personal connection and true security by providing it selflessly, enacting a family bond. It avoids the impersonal market economy of payments for services accompanied by contracts specifying conditions, certifications, rights, claims, indemnifications, and limitations of liability. So the term has power that derives from the values it carries. It conveys a sense of something good and right. However, because of its power and appeal, the term and the care work it implies help a dysfunctional system seem more functional and may put a damper on the call for change.

The need for change, however, is pressing, and family caregivers are essential to solutions that are both caring and cost effective. Families can become a critical component of systemic reform if the scope of their work is recognized and if health care institutions and other stakeholders invest more resources in both community-based home care and in more supports for family caregivers themselves.

Policy Directions and Promising Practices

In order to think concretely about new directions, we must take into account the key elements of public policy that shape the delivery of geri-
One theme that unites all policy discussions in this area is the looming financial crisis that faces the two major universal entitlement programs, Medicare and Social Security, that shape the delivery of health care and retirement income. We often hear that Medicare costs are spiraling out of control and that Social Security will not have enough funding to see the baby boomers through their retirement years. Another theme in policy discussions is the debate about the effectiveness of federally funded elder care services and the level of funding that should be allocated to the Administration on Aging (AoA) in each budget cycle. When cuts are proposed, policy discussions turn toward the core programs of the AoA, including the National Family Caregiver Support Program, established in 2000 under the Older Americans Act, and its grants to the states, which support a broad range of services and training.

In most policy discussions, as with this one, family caregivers appear in the context of debates about the financial and humane value of home care as opposed to nursing home care. In this context, caregivers are the victims of undersupport for home care and figure in policy proposals for a financial infrastructure that responds to the full needs of families caring for elders.

What is missing from much of current policy debate and discussion is a way to link empirical information about the work that family caregivers do—both in homes and in health care institutions—to the development of greater resources and more coordinated planning for high-quality, community-centered geriatric care. There is no one sector, public or private, that can take on this task alone. Rather we need to involve all the key stakeholders in elder care in a broad-based public discussion that brings the needs of health care institutions, community agencies, elders, and their families into alignment.

A first step in designing a better system of geriatric care is to identify policies or proposals that are grounded in the daily work and unmet needs of family caregivers. Based on our observations and analysis of family caregivers, we identify six key areas for future policy development and suggest what we see as promising practices that would concretely address the needs of family caregivers.

**Elder Care Information**

While most government-funded agencies have extensive elder care databases, many family caregivers do not know how to access these agencies or what to ask for when they do. We need greater investment from state
governments in providing accessible, user-friendly information so that caregivers can more easily learn how the elder care system is organized and how to find needed services and other resources. We also need health care professionals — whom caregivers do know how to find — to play a larger role in the distribution of elder care information. Our data suggest that when caregivers receive well-organized information about elder care services from their own doctor or health care provider, they see it as highly valuable support.

Acting on these findings, the MIT Workplace Center published a *Family Caregiver Handbook: Finding Elder Care Resources in Massachusetts* in 2007. The handbook is being distributed via state-funded elder care agencies in communities throughout Massachusetts and major health care providers in the greater Boston area. We are targeting these organizations as distribution partners in an effort to create coordination between the two components of the geriatric care system on which caregivers most rely — health care providers and community-based services — two components that are often poorly connected.

**Medical Records**

The quality of medical records and their cross-institutional availability has improved with the development of a system of electronic records replacing paper, but there are still gaps in the information that is captured. As our data show, family caregivers know the details of patients’ medical histories and current medications — details that often escape records transferred from one institution to another — but doctors and other providers do not routinely recognize caregivers as essential sources of information. Health care professionals need to solicit and incorporate family medical knowledge into the permanent medical records of elderly patients, and health care institutions need to develop new intake protocols that facilitate this process. In areas in which the privacy provisions of HIPAA regulations prevent the sharing and pooling of information among providers, patients, and families, the regulations need to be revised.

**Respite Programs and Support Groups**

There are two parts to the problem of expanding the ability of caregivers to use respite programs. The first is educating caregivers about what respite is, what programs are available in their community, and what the value of using these services is. The second is expanding existing services.
Although many policy makers call for expanded respite programs, they rarely advocate the need for caregiver education and self-assessment — and this links back to the need that caregivers have for accessible, user-friendly information. Greater investment from federal and state agencies is needed to expand these programs and to provide respite, both for planned stays and for emergency stays. By expanding the number of institutions that are willing to house respite programs — reaching out to continuing care retirement communities and hospitals, for example — the current pressure on small community adult day programs can be alleviated, and the needs of caregivers can be better served.

**Flexible Work Arrangements and Leave Policies**

Expanding supports for employed caregivers requires action from private employers and state governments and greater coordination between the two. Many employers have begun to recognize the pressures of elder care on their employees and the costs that these pressures produce in terms of absenteeism and loss of skilled workers. A number of the caregivers in our sample had left or were leaving their jobs due to lack of flexibility, and the number of caregivers leaving the workforce is rising nationally. Making flexible work arrangements more available can be a win-win situation, giving employees the ability to spend time with elderly relatives and creating a more stable and productive workforce for employers.

With regard to leave policies, efforts to expand the Family and Medical Leave Act (FMLA) are underway in many states. Legislation is being considered on both the state and federal levels that would expand the number of workers covered by the FMLA and would provide some level of wage replacement during a leave. One promising development is the passage of a paid family leave bill in California based on an employee payroll tax. A 2007 report by the California Senate Office of Research found that the new law has benefited over four hundred thousand Californians with a variety of caregiving needs, including elder care. This experience should be instructive for shaping paid leave programs in other states (Sherriff 2007).

**Expanded Training in Geriatric and End-of-Life Care**

With more people living longer, there is a pressing need to expand professional training in geriatric and palliative care in order to provide elders
with high-quality health and personal care—and to provide family caregivers with the understanding, support, and medical advice they badly need. The experience of our interviewees shows that a physician trained in palliative care can make a dramatic difference to elders and caregivers at the point at which approaches to treatment need to shift from cure to comfort.

Medical and nursing schools need to take the lead in finding ways to train the next generation of doctors and nurses to meet the special physical and mental health needs of older patients. Professional associations can also play an important role in focusing more of the continuing medical education courses they offer on geriatric care issues.

Multistakeholder Approach to Elder Care and Caregiver Support

As public, private, and nonprofit institutions all play a role in elder care, a multistakeholder approach is needed to secure more resources for the care of our eldest citizens.

Massachusetts is developing a promising multistakeholder model through the creation of a state-based Work-Family Council that would involve employers, labor, community groups, and others in finding solutions to a range of issues involving employment and family needs. This type of council could provide a public forum for discussing elder care and caregiver support policies, which could include pilot programs in workplaces, new partnerships among community agencies, and recommendations for legislative policy.6

While many players are needed to bring greater cohesion and coordination to the geriatric care system, health care institutions have a special role to play as the key providers of the medical care so essential to a good quality of life for elders. Hospitals, nursing homes, HMOs, practice groups, community health services, and insurers need to lead the way in recognizing the essential functions now performed by family caregivers and in creating new organizational systems to support those functions. If the work of families can be acknowledged and valued by these institutions, then family caregivers can move out of the shadows and take their

6. A bill initiated by the Massachusetts Institute of Technology (MIT) Workplace Center to establish the first such council in the country was passed by the Massachusetts legislature in December 2006, but it was pocket vetoed by outgoing governor Mitt Romney. It was refiled in January 2007.
rightful place as key contributors to a system that provides high-quality health care and personal care for elders.

References


