

Working Paper

*Rethinking the Job of Family Caregivers:
A “Shadow Workforce” in
the Geriatric Health Care System?*

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INTRODUCTION

Defining “Family Caregiver”

The term “family caregiver” has become something of a term of art in the present parlance of American health care. Its meaning is somewhat ambiguous as it can refer to someone providing medical or personal care to a family member of any age. But generally, it names the figure who, at some time, takes care of a child, a parent, a spouse, or another relative who is receiving medical care from professionals and needs additional care at home, or support of some kind in a hospital or nursing home. For our purposes in this paper, we will focus on family caregivers of elders. Given the overall aging of the population, the imminent retirement of the baby boom generation, and the likely consequence that increasing numbers of workers of both genders will be called on to care for their elderly relatives, this aspect of family caregiving is in need of intensive study.¹

The term, combining family and caregiver, evokes instant approval. Providing care is a good in itself. Providing it selflessly, enacting a family bond, operating outside the market economy of payment for services accompanied by contracts specifying conditions, certifications, rights, claims, indemnifications, and limitations of liability— caregiving is an act that satisfies a human desire for personal connection and true security. 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 "family caregiver" is masking, possibly serving to reinforce, a number of problems in the current provision of medical care for elders. For one thing, caregivers are taking on medical tasks well beyond the level of training that most have. This produces both stress and anxiety for those doing what is effectively hands-on nursing and the danger for those cared for of possibly serious mistakes. But beyond the home, the consequence of extensive family caregiving can be to reduce attention to inadequate staffing levels and an uneven quality of patient care in health care institutions and home services. In general, this tradeoff goes unseen and unexamined as the work of home care is accepted by caregivers and health care professionals alike, not as work, but as simply natural acts, right, to be expected.

¹ There were 36.3 million people over 65 in 2000, and it is projected that there will be 86.7 million by 2050. (2000 Census, U.S. Census Bureau) There were 33.9 million family caregivers of people over 50 in 2004, and it is projected that there will be 81 million by 2050. (*Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004)

Current Conceptions of the Family Caregiver: the literature

Over the last twenty years a substantial literature has developed on family care and the family caregiver. Feminist analysis has highlighted the gendered nature of family care work, and documented how little the traditional caregiver role has changed despite the large number of women who now work outside the home, posing a challenge to gender equality. (Tronto, 1993, Hooyman and Gonyea, 1995, Harrington, 1999, Folbre, 2001, 2004, Garey, et al, 2002) These studies have argued that family care is “unpaid work, “that this type of work has been largely invisible, and that this work is highly valued by those who receive it, as well as highly valuable to our society.

Another line of research on family care has focused on the employed family caregiver (Googins, 1991, Neal, et al, 1993, Moen, 1994). These studies have documented the difficulty of managing childcare and job responsibilities, elder care and job responsibilities, or both kinds of care - the famous sandwich generation. (Scharlach et al, 1991, Merrill, 1997, Doty, 1998, Maitre and Stephens, 2003) Many studies use time diaries to capture and quantify hours spent and resources expended, and this data has provided a more in-depth, if not complete, picture of care work. (Bittman, 2004) Although childcare has received more attention in the past, elder care is gaining increasing attention due to the demographic shifts described above.- These studies 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, 1994, Medjuck et al, 1998), and the costs to business of not providing flexibility, in high absenteeism and turnover and low productivity. (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 et al, 2000, Lee et al, 2001) These projects include both those that are employed, as well as those who are retired or never worked. Taken together, they document high levels of stress and stress-related illnesses, anxiety disorders and depression. (Lechner, 1993, Starrels et al, 1997) Family caregivers are often extremely fatigued, and those lacking respite are at risk of compromising their own wellbeing to the point of jeopardizing their ability to provide care. Some studies suggest job interventions for supporting employed caregivers (Donaldson, 1995).

Finally, there is an extensive literature - beyond the scope of this paper - that links the work of the family caregiver to public policy debates and options. In policy discussions, family caregivers generally appear in the context of debates about the financial and humane value of home care for elders—as opposed to nursing home care. In this context they are the victims of under-support for home care and figure in policy proposals such as compensation for family care and programs for respite care, along with the call for increases in paid home health services. (Silverstein and Parrot, 2001) A portion of this literature focuses on current programs for funding the health care and personal care of elders, specifically Medicare and Medicaid, and asks what reforms and changes are needed. (Stone, 2000 and 2003) Other studies focus on developing new mechanisms for supporting elder care, and some of these proposals are based on calculations of the value of family care measured in dollars (Arno et al, 1999, Wolf, 2004, Netten and Beecham, 1993) or estimates of gross household product (Ironmonger, 1996).

A Different Approach

Much of this research 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, 2004, Wiles, 2003, Ungerson, 1995, Walker, 1995, Arber and Ginn, 1992) In this dichotomy, “formal care” is that care provided in institutions where the providers are trained and paid for what they do, and “informal care” is provided outside of institutions where the providers are untrained and unpaid. (Bittman, 2004) We are challenging this distinction with respect to family engagement in the care of elders.

Using a sample of family caregivers who are providing elder care, we will show that the distinction between formal and informal care does not reflect the reality of what family caregivers do. We will argue that despite the lack of formal training and monetary compensation, these family caregivers are an important part of the geriatric health care workforce. However, we call them a “shadow workforce” because the care they provide - especially inside a variety of health care institutions - is largely unseen and unrecognized. These caregivers move constantly - with their elderly relatives - from doctors’ offices to hospital, to rehab, and home - and often back into hospital or rehab - playing a significant role in both formal health care institutions *and* informally at home. In fact, it is their work in a variety of in-patient and out-patient settings that is providing some cohesion among the pieces of an only loosely joined geriatric health care system.

We will show that by linking the domains of health care institutions, community services and home, it is possible to envision a more coordinated system that utilizes the complex work of family caregivers by providing the supports that they need. Recognizing the cross-institutional nature of family caregiving for elders also suggests a strategy for gaining needed supports. The cross-section of stakeholders—public sector agencies, non-profit and for profit health care providers, community-based service organizations—that necessarily work with families in the presently unwieldy system might see the benefit of joint action in securing the needed supports.

Using the vantage point of family caregivers of the elderly, this paper will identify a number of specific problems within the current system of geriatric health care and places where reorganization is needed. By looking at what families are actually doing at points where the institutional blocks compromise the care of elders, we will highlight both what families do well and what families could do better with better supports.

THE STUDY

The Methodology

This paper is based on two and a half years of fieldwork in the health care industry in the northeastern United States. 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 multi-specialty practice group. We conducted work observations in a variety of health care facilities, and interviewed team members and some spouses about how they manage their daily work lives and family lives. We observed the teams trying – with some difficulty - to coordinate their work across a complex and fragmented health care system. While they do to some extent follow patients from acute care hospitals to rehab facilities, their contact with patients is fairly short-term because many hospitals and skilled nursing facilities have shortened the length of patient stays to control costs. Patients are being discharged to home even though they still require significant care, and while the teams can maintain some home contact, their ability to do so is subject to limited staff resources.

In the course of our observations of team members and their interactions with patients and families, it soon became apparent to us that the family members are the ones who have long-term relationships with these elderly patients and are providing care in all venues. We then began to study the family role directly. We conducted in-depth interviews with 50 family caregivers whose elderly

relatives had been patients in the prior year in one of two in-patient rehab facilities in which the teams had supervisory functions. With introductions from team members, we worked cooperatively with senior managers in these facilities to contact family members; we sent letters requesting voluntary participation and assuring confidentiality in the use of all interview data.² Some caregivers responded by sending back a form, while others responded through follow-up phone 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 semi-structured interviews: the majority were conducted in caregivers' homes and taped, while some were conducted on the phone. The same interview protocol was utilized in both situations. The data were then coded according to twelve themes that recurred in the interviews.

The Sample

Most interviewees were still active caregivers at the time of the interview, although a small group had recently lost the person they were caring for. Not surprisingly, given the gendered nature of family care work, two thirds of the caregivers were women. And not surprisingly, given that the life expectancy of women is longer than that of men, most of those cared for were female relatives, usually the mother of the caregiver. The caregivers ranged in age from their early 40s to their late eighties, with the majority being in their 40s and 50s (70%). Half of the group was employed either full-time or part-time, one third were retired, and a little over 10% had left the workforce temporarily to accommodate their caregiving responsibilities. Over half of the group had at least some college education, and a quarter had a graduate degree. The sample is economically and racially diverse; roughly one quarter are eligible for publicly subsidized support services, a small group (10%) have household incomes over \$200,000, and the majority have incomes ranging from \$30,000 to \$100,000. Ten percent of the caregivers live outside of Massachusetts, and travel frequently to care for an elderly relative. Most of the caregivers we spoke with were born in the United States, although a few are immigrants from Europe or the Caribbean. One third of the group are minorities, including mainly African Americans and a few Hispanics.

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 65, so we feel reasonably confident that the

² Due to regulations under HIPPA and the terms of the IRB approval we received from the HMO, we were not allowed to interview any of the patients.

experiences of the caregivers we met reflect the experiences of others involved in caring for elders. (See Table 1.)

THE CONTEXT

The Problem for Family Caregivers: a geriatric health care system in pieces

The basic context for the work of family caregivers is a health care system that is uncoordinated, fragmented, bureaucratic, and depersonalized, an institutional setting that creates large and sometimes dangerous gaps in the care of elders.

In the course of treatment for an episode of illness, an elder, along with a family member, typically encounters multiple institutions with different systems of organization and communication and dozens of people—clinicians, administrators, technicians, aides, clerical workers—whose functions are often unclear to the patient and her/his family. The process generally begins with a family doctor or primary care physician (PCP) who may be in private practice, but more likely is part of an HMO or practice group. In any case, the physician would have to be someone who accepts Medicare coverage—unless the patient also has additional insurance. The same insurance questions also apply to specialists the patient is likely to see for common afflictions of the elderly—heart disease, cancer, arthritis, bone fractures, diabetes, possibly dementia. The specialists may or may not be in a group practice with the patient’s PCP, and if not may not have easy access to the patient’s medical record.

For care beyond doctors’ offices the patient and family caregiver encounter hospitals and possibly rehabilitation facilities or nursing homes, all with their own information systems and in-house nursing and technical staffs which may or may not have direct contact with the referring physician. In a hospital, patients might remain under the supervision of their PCPs or specialists, but increasingly are cared for by a *hospitalist*—a staff physician employed by the hospital who makes daily decisions about care, but has no previous knowledge of, or continuing relationship with, the patient. If the patient goes from the hospital to rehab and then to home under the care again of a PCP, coordination of information and caregiving practice among these separate institutions is necessary but usually not provided or facilitated by these institutions.

This becomes particularly complicated when a patient at home requires the support of community services which may include a visiting nurse, a home health aide, a medical equipment technician or visits to a specialized testing or treatment center. Add to this picture of unconnected pieces, the fact that all of them are under financial pressure and subject to episodic reorganization,

and the challenge facing elders needing health care and the family members helping them is enormous. It is in this context of fragmentation that the complex of role of family caregivers has developed.

THE FINDINGS

The Institutional Disconnects: a close look

In a health care system made up of multiple parts, sometimes with established cross-institutional procedures, but often not, breakdowns in the delivery of care are inevitable—as the following stories make vividly clear.

A Case Study of Disconnects: one family's experience

We arrive at 124 Perry Street in a working class neighborhood of Boston to interview Mr. Robert O'Malley.³ He lives on the second floor of a two-family home, and his two adult sons also reside there. He introduces us to his wife, Margaret, and their home health aide, Beatrice. We sit at the dining room table; Robert sits in his wheel chair as he is still recovering from a stroke. Margaret sits in her wheelchair in the living room watching a daytime TV show, she is recovering from hip replacement surgery. Between them they are dealing with seven chronic health conditions. Robert explains that Margaret does not really like television, but she cannot read or crochet – her two favorite pastimes – because she has been unable to see her ophthalmologist for a new prescription for her glasses. Margaret is frustrated, and Robert feels powerless in a system where the pieces do not fit together, and each piece is enmeshed in rules that make no sense.

Robert explains that Margaret is able to get from their second floor apartment down to the first floor – Beatrice moves her from the wheel chair to the electric chair lift. Margaret is also able to get from the sidewalk in front of their house to the wheel chair van – the men who work for The Ride can do that. But there is 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 wheel chair that goes in the van. The home health agency forbids 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

³ All proper names used in this paper are pseudonyms.

wheelchair men come and get her but they will not *touch* her beyond the stairs. They will not help her come down the [porch] stairs.

Mr. O'Malley's story is 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 is no coordination between a professional health care provider - Margaret's eye doctor - a home health care agency, and a community transportation service, all of whom are needed to get Margaret new eye glasses. There is literally a missing link in the system – a physical space Margaret cannot cross - because the health care provider and the community services on which Robert and Margaret rely are not being coordinated.

Multiple Providers, Multiple Institutions: the disconnect in health care

Family caregivers report lack of coordination both within health care institutions, and between institutions. Within hospitals, for example, family caregivers say that doctors often do not talk to each other about patients they have in common, and a few say they did not see the same doctor twice when their relative was hospitalized. One caregiver came from Texas to care for her elderly mother after knee replacement surgery. She explained that her mother had a pre-existing 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 jeopardized the quality of her mother's health care.

Family caregivers also experience this lack of coordination in the constant transitions that elders go through from hospital to rehab to home. Although most transfers from hospitals to rehab facilities go smoothly, this is not the case when a transfer occurs over weekend. Lillian Smith, who frequently travels to Boston from Chicago to care for her mother and step-father, described what happened when her mother was transferred to a rehab 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 seem to occur in the transition from rehab to home. In some cases, the patient is discharged prematurely. Most rehabs 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. But a number of caregivers report that homes were not checked before the discharge, and some say that the patient's ADLs and mobility were not good enough for them to be home. This can result in unnecessary falls once the patient gets home, which

often lead to re-hospitalization or more time in rehab, and this was reported by three caregivers. In other cases, the transition from rehab to home is too slow. One woman whose mother was dying of pancreatic cancer kept trying to get the rehab facility to let her mother go home, where her mother longed to be. The rehab staff delayed the discharge for reasons that were not clear to the family, and then when they did send her mother home the hospice services that were available were far less than had been promised, burdening the family with almost full responsibility for round the clock care.

Home Care Services: the disconnect at the community level

The biggest problem with lack of coordination occurs when family caregivers are involved in home care and 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 a few agencies that offer multiple services, but more often the family caregiver is calling separate places for home health aides, house cleaning, transportation, food services, prescription drugs, and specialized medical equipment and supplies.

At each of the transition points described, there is a need for geriatric case management to make sure that all the patient care and information is coordinated, but many family caregivers say they have not had access to such a person. At least part of the reason is economic. There are public and private agencies that have social workers and case managers, but the public agencies are available only to families with very low annual incomes, and the private agencies charge such high fees that they are effectively only available to those 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 affects him. He rarely receives calls from his mother's PCP, or her new oncologist, and the doctors do not seem to talk to each other, as best he can tell. He has no one to help with his mother's shopping and other errands, and does not know where to get her a better walker. With no one coordinating her doctors and the services she needs, Chuck spends his days – the time from Noon to 7 pm when he isn't 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. Recently, the home health aide that was coming into his mother's apartment a few hours a week quit, so he now must add finding a new aide to his "to do" list.

This lack of coordination at the community level has multiple negative impacts on family caregivers and their elders. Many family caregivers complain 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 organized around bureaucratic procedures.

For example, one caregiver, Rhonda Simon, whose mother has a degenerative disease and is 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 involved gathering documentation and letters from two of her mother's doctors, attending and testifying at a hearing. After her mother's request was finally approved she was told there was no apartment available and was put on a waiting list with no clear end date identified. She was finally contacted by the public housing authority and told they had a handicapped apartment, but it did not have the roll-in shower originally requested. The bathroom that was available would require her 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 private health care institutions and public agencies.

These pressures and frustrations take a toll on the employability, as well as the physical health and mental health of caregivers, is enormous. For example, Rhonda has been put on medication for depression and anxiety to help her cope with the pressures of caregiving. Chuck finds it difficult to sleep in between his third shift job and his afternoon elder care responsibilities. Lillian has had to make so many trips between Chicago and Boston that she has temporarily dropped out of the workforce until she can find a job with extensive flexibility.

Information Searches, Communication Barriers

Troubles for the family caregiver stemming from lack of coordination among health care institutions and providers is 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

These difficulties usually begin in the doctor's office or in a hospital. The doctor needs several kinds of information from the patient. They need to know how they are feeling physically, including the extent of pain and other symptoms. They often need to know a patient's medical history, especially if they have never seen the patient before. Regardless of prior knowledge of the

patient, the physician usually wants information about current medications. Elderly patients are sometimes able to answer the physician's questions themselves, but often they are not – either because of memory loss or other difficulties related to their illness. In these situations the family caregiver is critical, often describing the trajectory of a patient's condition, and providing information on the patient's history and medications. Some caregivers we spoke to told us they often knew about allergies to medications and pre-existing conditions that were not a part of the patient's chart or electronic medical record.

When a clinician lacks specific information on a patient's medical history, they may revert to standard protocols, sometimes with adverse consequences. In one instance, the use of a standard rehab procedure may have resulted in the death of a woman with multiple illnesses as she was being moved, via ambulance, from a rehab facility to a hospital. Her daughter said,

I think she just fell through the cracks in terms of being monitored... You know, there's all these standard protocols for all these various things that I don't think are in the best interests of the individuals that are going in. I mean you have to look at every person's physiology before you start pumping them full of stuff.

The patient and the family caregiver of course need medical information about the patient's condition. This 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 have difficulty tracking down information about what is wrong, or the expected trajectory of an illness - what to expect and how to prepare - increasingly they turn to the Internet for information. They become avid researchers, but, without a necessary level of medical knowledge, and when they cannot evaluate what they find, this too is frustrating.

The importance placed by patients and caregivers on hearing real information from a known person is clear in stories in which helpful informants appear by name. Laura, whose husband has had multiple brain surgeries, gratefully named the people who took trouble to provide her with precise information when she needed it. She had been reluctant to agree to surgery for her husband for a buildup of spinal fluid in the brain for fear of irreversible damage but agreed when a friend convinced her it was essential. In the course of the interview she named the friend, the neurosurgeon, his executive nurse, and his junior assistant. She was particularly grateful to the junior physician who "had a little more time and showed me on the screen...the black thing where the water, a little thin trickle of water was going down and its ok—there, it's within normal limits and he's back to

normal.” He had showed her in black and white that fluid was no longer building up and pressing on her husband’s brain. It was flowing out properly and he was back to normal.

Stories of good experiences getting medical information co-exist with stories of extensive difficulties accessing this type of information. By looking both at what works and what is broken in the current information system, improvements in the system can be planned.

Home Care Information

When caregivers are faced with the challenges of organizing homecare, 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. Again, caregiver stories identify areas for needed change.

“The folder:” undigested information

Many caregivers confront an urgent need for information and a baffling, non-personalized delivery of it when a family member is discharged to home from a hospital or rehab facility in need of considerable care from community services. If the caregiver has not had previous experience with such services, what each does and does not provide, the reputation of various service companies for quality and reliability, or even very clearly what particular services the patient will require, she needs guidance. She needs highly specific information, but prior to that she needs to know what information she needs. She may receive personalized helpful advice from a social worker in a discharge meeting, but many caregivers report that the main thing 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. But it is undigested, bureaucratized. What the caregiver needs is help with assessing it all, making decisions and choices.

Automated Phone Systems: depersonalized information

Once the patient is home – and the family caregiver is left virtually alone to know everything and do everything – their sense of frustration and isolation is exacerbated by the automated phone system. Laura, a spunky 70 year old woman, herself on medication for stress, is organizing complicated care of her husband who has had several brain surgeries for hydrocephalous and must be kept on a careful regimen to control diabetes and a potential for seizures. She says, “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 has substantial home care services, but the complexities of their medical conditions produce continual questions and the need for information from multiple clinicians. Laura manages this demanding process, but like many caregivers, she does it by fighting her way through a telephone maze paying a considerable cost in aggravation, stress, and time.

Of course, automated phone 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 savings 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, the patient’s wife, showed us two year old reports with such specifications such as 15 grapes a day, half an apple or a whole if it is small, and potatoes soaked for three hours to remove starch. “You are not getting anything like this now?” we ask. She says, “No, I don’t even know his weight. 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 coming 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 fulltime as a CNA in a nursing home and, without helpful guidance about her husband’s changing dietary needs, she had to “think everyday” about what food to fix for him—“which is very hard.” Just shortly before we arrived she had reduced her work hours from full to part-time.

Future Guidance: missing information

Another deep frustration for caregivers is the difficulty of finding information about anticipated needs. This is a common concern for adult children taking care of parents in fairly good health but facing decline that will require some form of institutional support. Judy, a school administrator, has begun to think about what to do when her mother needs more care and, in spite of familiarity with research tools, she doesn’t know where to go to find usefully organized information. She went on-line to look for adult day care in her area and could not find a helpful website 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 trajectory of their elderly relatives illness in order to prepare both logistically and emotionally, As Rosalind, whose mother has 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 issues and care issues are intertwined, and family caregivers need timely information about both to prepare for the future.

In general, caregivers suffer a frustrating imbalance between significant responsibility for someone’s health and lack of information and control over conditions for maintaining it. The experiences of caregivers who are seeking and having trouble finding information from professional health care providers, and who have critical information to share with these providers, clearly identify areas for change.

Gaps in the Health Care System for Elders: threats to quality care

As family caregivers of elders deal with the fragmentation of health care institutions and difficult access to information, they confront also a related set of problems that stem from gaps in the health care system for elders—a lack of needed services which families then seek to provide themselves.

Understaffing and Turnover

Caregivers report significant understaffing in hospitals particularly on the weekends and during major holidays. This can lead to medicines and diet not being carefully monitored, call buttons going unanswered for both medical and non-medical needs, and even to 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 centers on significant turnover among aides. Although a number of family caregivers seem 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 a particular patient.

This reality makes 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 it is in the hospital, rehab or home. When they feel that the care is not adequate and that their relative is unsafe, many caregivers take on additional care tasks they had been hoping to delegate resulting in considerable stress and fatigue.

Lack of geriatric and palliative care training

One dimension of care that has a significant impact on caregivers' assessment of elder care is the ability of professional health care providers to handle well the frightening, sometimes devastating issues facing seriously ill elderly patients and their families— the ability to listen to a family's concerns and to respond with sensitivity. In some stories this seemed at times to override issues of medical care, and the experiences caregivers report run the gamut of emotional interactions.

In one rehab 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.

In another facility, we heard about a deeply compassionate physician who took time in talking 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 every effort 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 are receiving stunning news, but the way in which it is communicated makes a qualitative difference in the ability of the family caregiver to talk with a parent or spouse or other relative about the difficult issues at 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.

Community services: lack of assessment and low quality

We have discussed above the information problem families face when an elder returns home from a hospital or rehab facility in need of significant care from community-based services and the family caregiver is handed a folder of brochures from various service providers, with no idea how to assess them. We note this problem again here as a gap in the health care system for elders. Just at the moment when high quality services are essential, hospital or rehab social workers who provide “the folder” take a more or less agnostic position. Most are not allowed by the rules of their institutions

to pass judgment, but rather to simply pass on information. This practice, while understandable from a liability perspective, only increases the anxiety level of family caregivers who not only have to make the calls to arrange the services, but also must make their own quality assessments – assessments that usually cannot be made before the service is in place. Some process of delivering specific information, perhaps with assessments and recommendations from prior clients, is needed.

Family caregivers also voiced complaints about the quality of various publicly-funded community services on which they rely for food and transportation. In fact, Meals on Wheels and The Ride received almost universal negative assessments in terms of the quality of the service, while at the same time being recognized as essential services for keeping elderly patients in their homes rather than in institutions. One caregiver, an adult daughter who cannot lift her very overweight mother, has to use The Ride to get her mother to doctor's appointments. However, she says the service is highly unreliable and has made her mother late for appointments, kept her waiting many hours after appointments, and occasionally did not come at all. Meals on Wheels got similarly negative reviews, and family caregivers report that the food delivered is neither hot, nor nutritious. Another adult daughter caregiver reported that the simple appearance of another delivery from Meals on Wheels made her mother – who is suffering from Alzheimer's – both confused and angry, adding to the difficulty of managing her mood swings. More important, the service was not set up to meet her mother's daily nutritional needs and special diet.

The ability of elders to eat well when they cannot cook, and to have mobility outside their homes when they cannot walk or drive (or only with great difficulty) are basic components of community-based elder care. But at this time these services are under-resourced and understaffed, creating a series of gaps in the infrastructure of the geriatric health care system that threaten the ability of families to keep their elderly relatives in their homes.

COMMENT: THE CAREGIVER RESPONSE

The issues highlighted - lack of coordination, lack of information, and significant gaps in the provision of health care 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 elder care system, therefore, is 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 - the family caregiver as victim. Our data confirm the findings of previous research that document work-family conflict, economic hardship, and negative health impacts. But we also establish the family caregiver as a person of agency and action who – seeing the deficiencies of the current health care system up close – steps into the breach and becomes part of a *shadow workforce*.

The caregivers we spoke to often take matters into their own hands - they play many roles and provide many kinds of care that are essential to the well-being of the elder they are caring for. There are two roles in particular that we will focus on: 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 accessible information needed to ensure the elder's health care be based on a more or less complete medical history. In addition, we document how some family caregivers act as *patient advocates* and *paramedics* to address problems with poor quality care, and how they construct their own family and community support systems to address the lack of specific supports for their work.

The key point about what caregivers do is that they are not simply responding to the personal care needs of the elder they are caring for. This decontextualizes family caregiving. Our analysis places the family caregiver in all domains of a geriatric care system that includes both health care institutions 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. They are continually called upon to fill institutional needs of the system, not just personal needs of an elder.

Becoming a Geriatric Case Manager: “There is no one person who knows everything”

These are the words of a woman who cared for her mother until she died of complications from multiple illnesses. She does not allege wrong doing, but bemoans the simple fact that of all the people involved in her mother's care there was no one – except herself – who knew all the pieces, all the medical pieces, the emotional pieces, the logistical pieces of her mother's care. The fragmentation and lack of coordination of the current health care system has been described above,

but family caregivers do not simply accept that as a given, some personally become the glue that holds the pieces together, the links in a broken chain.

The family caregivers we spoke to do not use the term “geriatric case manager” to describe what they do, but their interviews are filled with the details of such activity. First of all, they are managing relationships among medical doctors and between these doctors and other medical 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. These two facts converge and mean that any one family caregiver may be dealing with multiple doctors simultaneously. The caregivers we spoke to are dealing with four doctors at a time on average, a few reported between five to eight doctors at a time. There is the elder’s primary care physician (PCP) who is supposed to play a coordinating role, but oftentimes does not. A referral from the PCP is needed in order to see a specialist – and many phone 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 the family caregiver to suggest to one physician that he or she needs to consult with another physician.

Rhonda Simons’ story is fairly typical for family caregivers dealing with an open-ended long-term care situation. Her mother was suffering from multiple chronic illnesses, so Rhonda had to stay in touch with her mother’s PCP, cardiologist, ophthalmologist, orthopedist, orthopedic surgeon, and psychologist. Each specialist means a discrete set of doctor’s appointments that have to be scheduled, follow-ups at different intervals that have to be tracked, and prescriptions that have to be obtained and filled, taken together these tasks are very time consuming for family members.

And that is only the medical piece. For an elder who being cared for at home, a family caregiver must be in contact with a home health agency to arrange for an aide to assist with personal care, and often a separate agency to do a house cleaning. There is often a need for a visiting nurse, a physical therapist or occupational therapist, and these involve calls to another agency. In addition, a family caregiver must find a reliable medical equipment company for walkers, wheelchairs, IV poles, bandages, commodes and safety devices. For elders who have low-incomes, their caregivers may also access services through publicly funded services, such as The Ride, Meals on Wheels, and the Housing Authority - three more agencies, three more sets of calls.

But it is not just the calls. 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 are changing. 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 try to establish trust with yet another stranger. One of the caregivers told us that she doesn't mind if the home health aide who cares for her father is late, as long as she comes. In fact, she goes 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 for keeping this aide in her employ and minimizing turnover. This family caregiver is combining 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 that many health care institutions are grappling with. 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 is using has computerized its medical record, the information may not be easily transferable to another health care institution where the same patient is being cared for. And caregivers report that HIPPA privacy regulations create 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 the family caregiver.

Family caregivers report that they are often the ones who are able to supply key pieces of medical information in a timely manner. When elderly patients are examined by a physician they have not seen before they are often asked what medications they are on, and it is commonly the family caregiver who can name the complete list. Family members are often aware of allergies to medications and/or foods that are not in the medical record, and 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. But even for patients with no loss of cognitive function, it is difficult to remember all the information about diagnosis, treatment and test results that their doctor may need, and the caregiver's knowledge is often needed to create a more holistic picture of the patient's medical history.

Family caregivers often have a better understanding of what the patient looks like when they are healthy than a doctor who meets 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 nurse during her mother's recent hospitalization that a diagnosis of a heart attack was made. Another caregiver kept reporting to the hospital nurses that her mother's eye left eye was drooping 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 show a high degree of ingenuity in creating systems for managing all the medical information they know. In the course of our interview with Lillian Smith she described her system of logbooks and files. She is a long distance caregiver, adding to the challenge of information management. She is responsible for her mother and her step-father, both of whom are dealing with multiple chronic illnesses. She has created files for each of them: one sheet has names and phone numbers of doctors, one has names and phone numbers of community health services, and one has lists of medications. Then she creates logbooks for tracking things on a day-by-day basis. For example, her mother is diabetic, so there is one page for tracking her blood sugar, and another for tracking her weight – information the doctor needs to see if a certain medication can be reduced. She proudly tells us that her mother takes her logbook when she goes to visit her PCP. This information also becomes critical in an emergency situation. Lillian explains:

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 step-dad 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,' and know, because I know how important that is, and they ask you all the time.

One wonders what happens to the elderly patients who do not have files and logbooks to rely on, 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 in to the breach

The role of family caregivers as members of the geriatric health care workforce is apparent in hospitals, rehab facilities, and homes, and at times they take on specific staff functions. In hospitals, they monitor medications and diet, tell the doctor what the patient is feeling if the patient cannot, collect information on diagnosis, medications and follow-up care. In skilled nursing facilities, given current high number of patients for each staff member, they do everything from going to get help when a call button is not answered, to cooking and bringing in food when a patient is refusing to eat

the institutional food, to assisting with personal care when staff are not available, and collecting information for the transition to home.

Their role at home usually includes a significant amount of medical care, along with personal care. They are asked to dress and monitor open wounds, start and monitor IV pumps, dispense medications at the right time of day and in the right dosage, check vital signs, monitor blood sugar levels, weight and dietary requirements, especially for elders with diabetes, kidney failure and heart disease. To reduce the work of family caregivers to that of personal, informal care really misses the essential role these family members are playing in the health care of elderly patients. They may not be full-time members of the health care workforce, but like paramedics they provide both routine and emergency care.

Family members are like *quality control experts* as they monitor the health care their elderly relative is getting and act as *patient advocates* when quality is lacking. One woman who was caring 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 that she watch her husband till 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.

While this example is somewhat extreme, it is part of a group of examples that also carry fairly significant health consequences. These include reports of waiting long periods of time for antibiotics to treat an infection, or pain medication being started too slowly, or morphine 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 rehab to home. One man, a priest by vocation, explained how the discharge meeting for his father was poorly handled. His father was mentally competent so the staff spoke to him alone. Being of a generation that puts doctors on a pedestal, his 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 rehab, family caregivers are needed to accompany patients to follow-up appointments and often are needed to act as advocates in that setting. Caregivers report they often ask questions the patient has not raised, ask for additional tests, or request a second opinion. The patients themselves are often too overwhelmed with a large amount

of new information and the emotional stress of their illness. The family member, while not emotionally uninvolved, often has some perspective, and can take notes and present information to the patient after the appointment. In this way family caregivers become translators, making the language of the professional health clinician accessible to the lay patient.

Creating Caregiver Support Systems

The extraordinary ingenuity, determination, and acquired skill of family caregivers goes a long way toward providing needed care for elders, but in the present state of health care practice, too great a caregiving role is being left to families, at too great a cost both for the quality of care of patients and the wellbeing of the caregiver. Families want to take care of their elderly members as they have traditionally done, but with systems that measure physician 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 the family caregiver. These institutions depend on family members, but the system neither recognizes the full extent of their role, nor does it offer a formal assessment of the needs of the caregiver or a mechanism for responding. The needs of the caregivers vary, depending on their own age, health status, and the emotional and physical health of elder they are caring for. But it was striking that very few caregivers we interviewed had access to a support group or respite program, only three in fact. 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.

Again, we found family caregivers taking the situation into their own hands and constructing their own support systems, either to help with transportation and personal care, or to support themselves emotionally. The most common support systems were comprised of 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 living there as well and sometimes another relative. For example, Angela Thompson, a retired aerospace worker, lives in a three family house. She and her 85-year old mother live on the second floor, her brother lives on the third floor and her cousin lives on the first floor, so she has relatives very near to help her with her mother’s care. In some families, when one sibling lives locally and the other lives out of state, they

devise a way of sharing the caregiving so that the person living locally is not the sole person responsible for their parent's care.

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 militate against shared care, and this can become an additional source of stress for the family caregiver. About a quarter of the sample did not have an extended family support system, and in these cases long-term home care is not sustainable. One woman whose siblings refused to help with the care of their mother, managed to keep her mother in her own home for seven years. But 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.

Community support is not as common as extended family support, but some caregivers are able to draw on individuals and resources beyond their own families. A number of caregivers report support from their religious communities. One elderly woman caring for her husband can no longer drive, so her minister frequently drives her to the grocery store and to doctor's appointments. Another woman was able to find a couple to provide live-in help with her husband through a friend at her church. A man who took early retirement to care for his wife and is very active in his church told us that he has not yet called on his fellow congregants, although several visit. He is waiting until his wife is more needy to enlist their help, showing that a family caregiver can be quite strategic in his or her use of community support and resources.

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

In sum, family caregivers do not wait for professionals or outside agencies to provide support. They turn to family, to those they live near, pray with, and socialize with, to create a support system that can help them on a practical level and give them the strength to be involved in long-term elder caregiving. Although caregivers face many challenges and stressors, they must be seen as members of households, families and communities who have resources they can draw on. This is another example of how the distinction between formal care and informal care does not capture the work of family caregivers. Even in constructing their own personal support systems,

they draw strength from family bonds, non-familial relationships and groups, and membership in a diverse set of community institutions. But far more institutional support is needed as well.

CONCLUSION

Family caregivers are important members of 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. The distinction that is frequently used in discussing elder care 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 private homes; and second their work combines personal care, medical care, and infrastructure support. In addition, they 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, they perform important integrative functions and add significant value to the quality of care and help to reduce the costs of health care.

The current impact of what family caregivers do on families themselves, and on the health care system, is contradictory. For family caregivers, home care is something they want to do, it fulfills a desire to help, to provide assurance, to ease suffering for people close to them—but the burden of providing needed care for elders can be heavy and even harmful to the health of those who undertake it. For healthcare institutions, the care work of families helps a dysfunctional system to be more functional, but it also masks problem with the health care system, and may unintentionally put a damper on the call for change. But the need for change is pressing and family caregivers are essential to solutions that are both caring and cost effective. They can become a critical component of systemic reform if the scope of their work is recognized and if we, as a society, invest more resources in both community-based home care and in more supports for family caregivers themselves.

In order to achieve quality home-based geriatric care, the key institutions involved in elder care need to bring greater resources and more coordinated planning to this effort. Following from the findings discussed above, there are four key issues that we think deserve broad-based public discussion as a first step in designing a better system of geriatric care.

- *Geriatric Case Management:* Health care institutions and community service organizations who employ geriatric case managers need to assess the ratio of geriatric case managers to patients, ensure that caseloads are consistent with quality care, and make sure

families are actively encouraged to take advantage of these services. In addition, consultation and coordination between case managers and family caregivers must become a regular and essential part of out-patient medical appointments, and the discharge process from hospitals and rehabs to home.

- *Information:* Family caregivers need a better information system, one that is clear and easy to access, about key medical issues and home care services. Harnessing the power of the Internet, as well as print and electronic media, could be key to making elder care information much easier for family caregivers to find and use. In addition, health care professionals need to create a systematic way to solicit and incorporate family medical knowledge into the permanent medical records of elderly patients.
- *Caregiver Support:* For caregivers who are employed, there is a need to ensure flexible work arrangements and leave policies, and a climate in the workplace that makes it possible to utilize of these policies without any kind of penalty. For all caregivers, expanding respite programs and access to caregiver support groups are important to enabling caregivers to provide good care without endangering their own health. Also essential is the development of training programs to give family caregivers a greater knowledge base and an expanded skill set to do the essential work they are now doing on their own often without appropriate training.
- *Skilled Care at Home:* The more elders are cared for at home the greater the need for skilled professionals – doctors, physician assistants, and nurses – to provide care in the home. The use of mobile teams of health care professionals is being pioneered by some health care providers in Massachusetts, and these innovative programs need to be evaluated for their benefit to patient care and family support, and assessed for possible replication in a variety of community settings.

As public, private and community institutions all play a role in elder care, we must take a multi-stakeholder approach in securing more resources for the care of our eldest citizens. While many players are needed to bring greater cohesion and coordination to the 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 rightful place as key contributors to quality health care and personal care for elders.

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Table 1. The Demographic Profile of Family Caregivers of Elders:

<u>Our Sample</u> (N=50)	National Profile⁴
66% women	63% women
70% in 40s and 50s	65% between 35-64 (mean = 47 years old)
65% earn \$30K-\$100K	52% earn \$30K-\$100K
34% minorities, mainly African American	25% minorities, mainly African American (11%)
50% employed, either part-time or full-time	57% employed, either part- or full-time
over 50% have at least some college	67% have at least some college

⁴ Source: A national survey of 1,247 family caregivers conducted in Fall, 2003. (See National Alliance for Caregiving and AARP Report, *Caregiving in the U.S.*, 2004)

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