

Financing Long Term Care: A Family Perspective of Private and Public Responsibility

This study provides insight into financing long term care decision making through a family policy lens. In-depth interviews with 45 families coping with long term care decisions provide insight into the role public and private resources play in paying for community-based and nursing home care, and the dynamics surrounding Medicaid estate planning decisions. Four criteria are recommended for policymakers to consider if long term care delivery and financing is to be improved for elders and their family members as the ultimate consumers of long term care.

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There is no doubt that the existing long term care financing "system" is proving costly in many ways to the chronically ill, their families, and bureaucracies involved. Many questions exist about the role private family resources as well as government programs (such as Medicaid) can and/or should play in financing long term care. Medicaid-related headlines and ads for professional advice on "avoiding nursing home costs" have led policymakers to ask if elders are qualifying for and using Medicaid who don't really "need" it? Are families engaging in Medicaid estate planning, a practice of intentionally and legally transferring wealth to family members to qualify for Medicaid coverage and avoid using personal assets to pay when long term care is needed? What family resources are really being used to meet the care needs of elders?

How one goes about understanding the role private and public resources play in long term care of elders depends in part upon whether one takes a family or fiscal policy perspective. A majority of existing research has taken a fiscal policy perspective and has attempted to examine the impact of how resources are being used on state or federal government expenditures. In this study, the focus is on examining the financing of long term care decision making, including Medicaid, largely through a family policy lens. This means understanding from family members coping with long term care decisions what impact current long term care policies and options have on family decisions about providing and paying for long term care. Utilizing such a lens provides insight into how long term care systems, including government programs and policies can be improved to be more "family friendly."

Specific questions addressed in this study include: 1) Are elders planning ahead to protect against long term care risks; 2) What types of family and

government resources are being utilized to plan for or protect against the risks of long term care; and 3) What decision making processes and dynamics impact Medicaid estate planning. Answers to these questions can help inform policy as decisions are made about how to allocate scarce resources to protect an increasingly elderly population against financially catastrophic long term care costs. The answers also provided insight for consumer educators regarding needed content and potential target audiences.

A few comprehensive studies have been published to determine the scope and prevalence of Medicaid estate planning. To date, most research has focused on understanding the impact of Medicaid estate planning on state budgets (Moses, 1990; Minnesota Department of Human Services, 1996) or nursing home use (General Accounting Office, 1988), rather than how families arrive at decisions or the impact of financing options on families. Some studies share anecdotal evidence from selected types of professionals involved in financing long term care that increasing numbers of individual are practicing Medicaid estate planning (Burwell, 1991, 1993; Moses, 1990, 1993).

Methods

This study was designed to gather in-depth insight into family decision making about allocating private and public resources when elders face long term care needs. Qualitative methods were considered the most appropriate for beginning to understand the dynamics of decision making given the multi-faceted and complex nature of financing long term care and the current lack of research. The methods chosen enable an in-depth understanding of the issue from purposefully selected samples.

Sample

Families involved in long term care decisions were recruited to participate during 1994. Two types of families were recruited, those with an elder already in a nursing home (n = 33) and those with an elder diagnosed with a chronic illness but still living in the community (n = 12). Compared to the majority of the elderly population, these families were more likely to be dealing with decisions about paying for long term care. Families were recruited through the assistance of family councils in nursing homes and support groups in churches, hospitals, and agencies serving caregivers and individuals with Alzheimer's and Parkinson's disease. Of the 45 total families recruited, roughly half were located in a metropolitan setting and half in a rural, agriculturally based setting.

Family members volunteered to participate in the study. They included a broad socioeconomic spectrum, from elders who lived on Social Security as their only source of income to those with a net worth of millions. A majority were middle class with accumulated assets up to \$100,000, not including the value of their home. Adult children also ranged across the entire spectrum of economic well-being. About three-fourths of the interviews were with the one family member most involved in financial and care decisions--typically a spouse if married, or an adult child (daughter or son). The remaining interviews were completed with two family members who were both involved in financial decisions. The elder in need of long term care and still living in the community typically participated in the interview, while those in nursing homes were unable to do so.

Data Collection and Analysis

Personal interviews were conducted by trained interviews using a semi-structured interview format. Questions focused on understanding the elder's health history, diagnosis and prognosis, and caregiving (including who was involved in providing care and assistance to the elder). Additional questions focused on decision making regarding care, paying for care, financial options considered and being used, amount and type of planning ahead, and perceptions about the current as well as future long term care system.

Interviews were transcribed and then coded to identify goals, decision making processes, resource allocation decisions, as well as roles and rules regarding private and public resources spent on long term care. Emerging patterns were examined for differences and similarities based on geographical location (rural/urban) and whether families were using community or nursing

home based care.

Findings

Are Elders Planning Ahead?

The vast majority of elders had done some type of planning ahead for retirement--but the retirement prepared for was both a shorter and healthier one than being experienced. Few elders planned to live so long or were prepared for the potential costs of long term care. Denial of potential long term care risks and costs and a great deal of hope that they would escape such costs seemed commonplace. Elders talked about the unpredictability of health care needs and costs as well as the inability to save enough anyway to meet possible care needs. Even elders who have been diagnosed with a long term chronic illness talk about "hoping" that a limited amount of care is needed beyond what family caregivers and their own resources could get them through. Fear and worry about outliving one's income and assets were very real for some, especially individuals 85 years and over. Fear about what the future might bring financially had some elders not refilling medications and doing without needed home care help.

"You saved and were careful and thought you were going to travel and do things and all of a sudden it all goes for nursing home care--you hope that it doesn't happen."
(Wife of husband with Alzheimer's in nursing home for 4 years)

A few families who had been approached by long term care salespersons had discussed the risks and cost of nursing home care. For many of the elders over 85, long term care insurance policies were barely on the market at the point when they would have qualified or been able to afford the premiums. It simply was not a feasible planning option. Younger spouses talked about not being able to qualify due to health problems, the high cost relative to their income, not being a "sure" thing, and different opinions among spouses as to the need for such insurance.

How Are Care Needs Being Met?

Family caregivers. Every family story included the key role family members' skills and resources played in keeping the elder in their own home or apartment and independent for as long as possible. As other research has suggested and the families in this study reinforced, it is the private informal resources of family members which provide most of the long term care for elders. The number of years in which family members assisted in keeping an elder independent ranged from 1-15 years. Without the intensive family caregiving years, paid help

would have been required, needs would have gone unmet, or different care settings explored. Families with an elder in the nursing home had provided a mean of 5.85 years of caregiving per family while families currently in the process of providing informal care had provided a mean of 2.45 years of care. The "costs" for family caregivers--both direct and indirect--are numerous and typically go unmeasured as well as unnoticed. The total expenditures that result from the 205 total years these 45 family members contributed are invisible and frequently unrecognized.

Community support. Community-based services played a key role in being able to make caregiving manageable and in meeting the care needs of the elder. In almost all families with an elder currently in the nursing home, some type of community support prevented earlier placement in a nursing home.

Family members talked about the importance of having a range of options to choose from in community services which were both affordable and provided quality care. For some, the availability of quality assisted living provides needed support between one's own home and the nursing home. For others, formal home care, adult day care, respite care, meals on wheels, and caregiver support helps meet either the elder or the family caregivers' needs. Family members also talked about doing without needed services because they were unavailable, not affordable, or because the elder refused to accept help from outsiders.

Many families experienced a spending down of their private resources while the elder was in the community. Income as well as selected assets were going to pay for assisted living, paid home care, and the frequent co-pays and deductibles not covered by Medicare or Medicare supplement policies. Costs such as dental and eye care, prescription drugs, or insulin were examples of costs typically being paid for out-of-pocket. It was not uncommon for assets from the sale of the home to be used for assisted living, or being able to live in an apartment or condo with some arranged services and support.

Nursing homes. A consistent and clear message from families was the desire to avoid nursing home placement. Families still in the community spoke often about avoiding nursing home placement and hoping that they would be the "exception" as the Parkinson's or Alzheimer's disease of the elder progresses. In reality, families come to the realization that nursing home placement may be the best way to meet the care needs of the elder. Feelings of guilt and failure for not having tried hard enough or doing enough are commonly expressed by the caregivers, regardless of how overburdened or overloaded their role may have been.

Of the families with an elder in the nursing home, elders were typically in the oldest-old age group, female, and widowed. Nursing home stays ranged from 1 month to 13 years with a median stay of 24 months.

Who is Paying for Nursing Home Care?

Of the 33 families in our sample with an elder in a nursing home, all but one had used family or private resources to pay for care during part of all the stay. Of the 32 who had entered private pay, a majority (25) remained private pay while seven had spent down and had qualified for Medical Assistance. Private pay stays ranged from 1 month to 13 years, with a mean of just over two years. In our sample the average family, then, had spent \$75,000 on nursing home care with future needs and costs being unpredictable (2.15 years of care times an average nursing home cost of \$36,000). These expenditures followed the mean 5.85 years of informal caregiving, and out-of-pocket payments for community support.

What about Medicaid estate planning?

Medicaid estate planning involves intentionally transferring assets owned by the elder to other family members to become eligible for Medicaid as the payment source for one's care. Awareness of Medical Assistance and the financial protection it provides for nursing home care varies. Most families hope nursing home care will not be needed, and therefore perceive no need to consider such planning. Even when an elder is diagnosed with an incurable, debilitating disease and there are expectations of increasing care, a majority of families do not appear to be consciously planning how they will meet such needs beyond their own caregiving resources. Some have listened and learned about financing options, but have not made specific plans. Some know there are government options, but are not sure about any of the details. Other have heard about Medicaid and consider it a safety net, should their own resources be depleted. Some know some details about transferring assets to become eligible, believe many other families are taking such action, but consider it dishonest, a loss of dignity, and a process that goes against their values and goals.

Most families learn about Medical Assistance upon admission to the nursing home and it is at that time that they begin to explore burial trusts and to specifically consider gifting allowed under the guidelines. Many families with an elder in the nursing home have established a burial trust so that money would be available for a funeral; but do not consider this to be Medicaid estate planning or a transfer to exempt assets under Medicaid. Gifting of \$500 or \$1000 to adult children/year might also be occurring but not considered

intentional transfers to become eligible for Medicaid. Families in the community often learn about Medical Assistance through support groups or through friends and may follow up with visits to a professional to learn about specific options.

Some families learned about Medicaid estate planning and made a variety of decisions. One of the 33 families with an elder currently in the nursing home had "programmed mom for Medicaid" by establishing a trust in which mom's assets will be inherited by an adult child. In this family, informal care and assisted living had been provided and paid for with family resources for 8+ years prior to needing nursing home care. The inheriting adult child is paying the extra amount for a private room. Another of the 33 families who had an elder in the nursing home had planned to apply for Medicaid after reserving \$60,000 for nursing home care. Assets had been rearranged to provide financial security for the remaining spouse and assets transferred to adult children with the expectation that the assets would be used for the frail spouse should the healthy spouse precede her in death. In this case, the Medicaid application was never filed as the spouse died after two months of private pay and seven years of intensive home care by the spouse.

"I could have taken it all and disposed of it, but I didn't. I just felt that we could pay this for some time, the state don't have to pay it as long as I can. I planned to pay about \$70,000 or so." (*Husband of wife with dementia*)

For some families who had already spent down or were in the process, knowing Medicaid was available as a safety net and that care would not differ depending upon whether they were private or public pay was a great relief.

"You see, we didn't think it would turn out this way. I feel really bad...I don't want my mother on the dole, I think that's terrible, but what else are we going to do? We sold her home and she had very little in savings. I'll pay for her private room." (*Daughter of mom in nursing home who spent down private resources*)

Public Policy and Education Implications

The delivery and financing of long term care is a complex policy issue which continues to be addressed through legislation, regulation, enforcement, and private sector initiatives. Medicaid eligibility requirements are being revisited, especially types and timing of asset transfers. The role of private sector funding mechanisms such as long term care insurance, and the availability of community-based services are some examples receiving consideration at the federal and state levels of government. Such policy discussions involve assumptions regarding the role of the private and public

sectors in long term care, the emotional and financial obligation of family members to provide care for elders, and inheritance rights. The voices and experiences of family members as the ultimate consumers of long term care offer important insight for policymakers as debates on long term care continue. Consumer and family advocates can play a key role in helping ensure policymakers hear and consider consumer perspectives.

First, it is important to recognize that both public and private resources are needed to help finance long term care. Families as well as various public programs are already spending significant amounts of their own resources. Resources being used by families include caregiving skills as well as income and assets to meet the needs of frail elders. Policymakers should question how far family resources can be stretched before needs go unmet and elders as well as family caregivers are at risk.

Claims that a majority of families are divesting and voluntarily becoming poor to qualify for Medicaid did not hold true for these 45 families. A few families were transferring assets in anticipation of becoming eligible for Medicaid. Gifts to family members were common and typically \$1000-\$2000/person, smaller amounts than allowed under current gifting laws. Gifts were often given and/or received with the expectation that they would be used to cover the costs of a private room or other expenditures not covered by Medicaid. It is also important to remember that not everyone who divests will eventually apply for or use Medicaid.

Future attempts to understand the prevalence of Medicaid estate planning should not simply focus on tracking dollar amounts of assets transferred among family members. It seems essential to understand why transfers are made, the goals families are trying to accomplish, expectations regarding use of assets, and the actual impact of the assets transfer. Getting answers on prevalence may not depend as much on willingness of family members to talk as much as how the questions are asked. The meaning of divestment and transferring assets varies among family members. Certain actions taken within legal guidelines may not be perceived as divestment or intentionally transferring assets to becoming eligible for Medicaid (e.g., burial trusts, gifting within allowed limits).

Improving Long Term Care for Families?

Family members involved in long term care decision making provide insight into what improving the current long term care "system" for family members would mean. Four key criteria are recommended as measuring sticks for policymakers and consumers to use as hard decisions about limited resources continue to be

made. Decision makers should be challenged to answer how specific policies and programs will accomplish each of the criteria.

Simplify and Integrate. The current delivery and financing “system” is too complex in terms of access, eligibility, paperwork, and being able to understand who will pay for what. Family members and professionals are spending limited resources on just trying to understand options and consequences to attempt informed decisions. The lack of integration in the delivery and financing of nursing homes, health and social community-based services, and acute care settings such as hospitals and care providers is a major source of frustration for family members trying to provide quality care for an elder. The complexity means that some families “decide not to decide” because the decision making is too overwhelming, and a majority of families must rely on a variety of professionals for information to understand potential options. Professionals struggle to keep up with changing policies and rules, and sometimes offer different interpretations of what options are legal or what the potential consequences of decisions might be for family members.

Build Supportive Systems for Families. Family members are trying to meet the needs of elderly family members by providing quality care and keeping them as independent as possible. To do so, they need access to a continuum of long term care services in a variety of settings. Elders and family members clearly prefer community-based care, but equal access, affordability, and quality issues must be addressed if such services are truly useable.” Services which assist and support informal caregivers as well as the elder can play a critical role in extending family and therefore public resources. Subsidized adult day care, for example, allows an informal caregiver to provide unpaid care, keep an elder at home, and prevent potentially costlier institutionalized care.

Provide a Safety Net. There are limits to the availability and ability of family resources—both informal caregiver skills and accumulated assets to pay for unpredictable long term care expenses. A continuum of quality community-based and nursing home care is essential to meet the needs of elders without social support and who have limited personal assets. The safety net needs to take into account the impact of eligibility criteria on both the elders’ care choices as well as on financial protection for a remaining spouse. Policymakers should learn firsthand what it’s like to complete a Medical Assistance application, the process of application, and the impact on family members. The lack of an adequate safety net will mean unmet needs, overburdened caregivers, and spouses at risk of financial

insecurity. As Medicaid is revisited and states struggle with fiscal responsibility, the risks to elders, their family members, and society as a whole must recognize that for some elders, Medicaid is their only option.

Provide Clear and Consistent Messages Regarding Financial Responsibility. Family members and professionals consistently emphasize the need for policies which provide more “givens” so that individuals can make informed decisions about how to best protect against the risks of long term care. As one adult’s child in his 40’s said: “If they keep shifting the target around, what most people find is that you never put an arrow into your bow. In other words, don’t plan, don’t set anything aside, because they are going to shift it on you and there is no point of doing it. You get a lot of gambling because it doesn’t matter anymore.” State legislatures continue to consider and make changes to make it more difficult to dispose of assets and become dependent on Medicaid. The discrepancy between what is considered legal and what is considered proper confuses both families and professionals. Consistent messages would help reduce the fear and worry about the use of private and public funds.

Prevention education is one tool to help provide clear and consistent messages regarding financial responsibility for long term care. Education is needed to help current and future generations understand the risks of long term care, the potential financial implications, and the range of family, private sector, and public resources available for protection. Myths about “who pays” continue and need to be replaced with a realistic understanding of financing options and potential consequences. Family members might be more willing to plan ahead for long term care and pay “my fair share” if they knew what their fair share would mean financially.

There is a critical need for educators who can provide a holistic view of long term care financing options and potential consequences. Consumer and family economists are ideal candidates. Too often consumers are faced with having to seek out information on various types of financing options from different sources of information (Medicaid, long term care insurance companies, financial planners). As a result, consumers may understand selected financing options, but not understand how the pieces fit together to provide adequate protection or the consequences of selecting certain options. To make informed decisions, consumers need a minimum of both credible and “plain language” information. Consumer educators can play a key role by filling these educational gaps.

Many decisions about delivering and financing long term care are facing policymakers. These decisions will have both direct and indirect implications for

heard as decisions are made regarding the allocation of scarce public and private resources. As solutions are examined, the consequences—including the true costs for elders and their families—should be thoroughly understood.

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Endnote

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