

7

Contents of Section

The Extent of the Problem

Caregiver Needs

Obstacles to Improvement

Encouraging Factors

Implications for Policy and Programs

Key Points

Critical End of Life Need #3: Support Caregivers

Death in Michigan most often follows a period of family caregiving—informal support and lay medical care provided by relatives, partners, and friends. The need for family caregiving is likely to grow in coming decades for several reasons:

- The population aged 65 and over will double between 2011 and 2030. By 2050 the number of residents aged 85+ will quintuple.
- Chronic diseases cause seven of ten deaths. Most often there is a period—sometimes years—of disability beforehand.
- Efforts to contain health care costs will continue. This means brief hospital and post-acute lengths of service and increased reliance on family care.
- By 2020, the nursing workforce is projected to be 20 percent smaller than needed (Buerhaus, Staiger, & Auerbach, 2000).

Nationally, 21 percent of adults provide unpaid care to a person aged 18 or older (National Alliance for Caregiving & AARP, 2004). They perform about 80 percent of the care for persons who need help with daily activities, including those at the end of life. If their services were replaced with paid assistance, the annual cost would be an estimated \$196 billion. This amount far exceeds annual payments of \$83 billion for nursing home care and \$32 billion for home health care (Arno, Levine, & Memmott, 1999).

While family caregivers save billions in expenses for health systems and payers, they do so at considerable cost to their own well-being. This section reviews the extent of the problem, caregivers' needs for support, obstacles to improvement, encouraging factors, and implications for policy and programs.

The Extent of the Problem

There are an estimated 1.6 million informal caregivers in Michigan. According to estimates based upon joint studies by the National Alliance for Caregiving and the American Association for Retired Persons (1997; 2004):

- These caregivers hail from nearly one of every four households.
- More than 1.2 million Michigan residents are caring for persons aged 50 and above. The average age of the care recipients is 75.
- Ten percent of caregivers rate their caring experience at the highest level of burden. They are more likely to be older and to report emotional strain (63 percent), physical strain (46 percent), financial hardship (34 percent) and fair or poor health (35 percent).

Who are these caregivers? According to compiled findings from national research, they have these characteristics (Family Caregiver Alliance, 2001):

- About 75 percent are female. Average age is 46.
- They spend an average of 20 hours per week caring for persons aged 65 and older. One in five spends over 40 hours per week, some giving constant care.
- Most provide care for one to four years; 20 percent do so for 5 years or longer.
- Half provide care with no outside assistance. Only an estimated 10 to 20 percent use paid services; they view this as a last resort.

How does caregiving affect them? While many family members find rewards in the role, there is substantial burden involved as well. Caregiving usually comes as an unexpected responsibility for which people are unprepared. To assume the role, caregivers must restructure their lives. They also must relate to the care recipient in new ways, and negotiating the new relationship may cause strain. Family caregivers are on duty or on call around the clock. Those who have never cared for a seriously ill person must learn basic nursing skills. This learning must occur under stressful circumstances, often with no guidance or support. The caregiver role increases over the course of illness, requiring further adjustments in the caregiver's life. The cycle is exhausting (O'Neill & McKinney, 2003).



About 1.2 million Michigan residents care for persons aged 50+. An estimated 120,000 of these caregivers are at high risk for physical, emotional, and financial strain. These vulnerable caregivers tend to be older and in fair or poor health.

There is strong consensus that caring for an elderly person with disability is physically and emotionally taxing for family members. Caregivers risk physical injury, ill health, emotional strain, and financial hardship. Elderly spouses are particularly vulnerable. These burdens of caregiving are described further below.

Physical Injury

One study of 988 terminally ill persons who were living at home found that they had these symptoms:

- 50.2% had a moderate amount or a lot of pain.
- 17.5 % were bedridden for more than half of the day.
- 70.9% had shortness of breath while walking;
- 35.5% had urinary or fecal incontinence.

More than 85 percent of these people required at least some help with daily needs; 35 percent needed substantial support and 29 percent required nursing care. Most relied completely on family and friends for personal care (50.3 percent) and nursing care (42.4 percent). Overall, only 34.7 percent received hospice or home care (Emmanuel, Fairclough, Slutsman, Alpert, Baldwin, & Emmanuel, 1999).

Another study of persons with severe, life-threatening illness found that 34 percent required considerable caregiving assistance from a family member. Of these individuals, 29 percent needed help with one or two activities of daily living (ADLs) and 20 percent required help with three or more ADLs (Covinsky, et al., 1994).

Caregivers usually have no training in moving, lifting, or turning seriously ill adults, yet they routinely perform these strenuous tasks (Rabow, Hauser, & Adams, 2004). This puts them and often the patients at serious risk for injury. A national study of 1,247 caregivers found that only 37 percent of those who provided the most intense care had received any training (National Alliance for Caregiving & AARP, 2004). More than 80 percent of these caregivers helped with three or more ADLs, including:

- Dressing (88 percent) and bathing (83 percent);
- Moving in/out of bed and chairs (83 percent);
- Toileting (68 percent) and changing diapers (53 percent).

This same study found that the 31 percent of caregivers who faced these most intense caregiving tasks most often were older and vulnerable to injury. They were aged 65 and above and rated their baseline health as fair or poor. Not surprisingly, 54 percent



More than 1/3 of persons who are living at home with terminal illness require substantial help daily.

Caregivers usually have no training in moving, lifting, or turning seriously ill adults. Yet they routinely perform these strenuous tasks.

About 1/3 of caregivers who provide intense care are older and in poor health themselves. More than half say that caregiving has made their health worse.

reported that caregiving had made their health worse, compared to 15 percent of all caregivers.

Ill Health

Caregiving leaves little time or energy for self-care. Family caregivers tend to put the needs of the ill person ahead of their own. This may cause them to abandon preventive measures and delay their own medical care (Rabow, Hauser, & Adams, 2004). In one study women who felt burdened by caregiving were less likely to eat balanced diets, exercise, or manage their stress (Sisk, 2000). A variety of studies report physical ailments among caregivers. Examples include:

- Elevated blood pressure, increased risk for hypertension, and doubled risk for coronary heart disease (Lee, Colditz, Berkman, & Kawachi, 2003)
- Poor sleep, poor immune function, and slower wound healing (Rabow et al, 2004)
- Increased cancer risk (Cameron, Franche, Cheung, & Stewart, 2002)

Caregiving can even be lethal for the elderly. The Caregiver Health Effects Study followed 392 caregivers and 427 non-caregivers for an average of 4.5 years. All lived with their spouses and ranged in age from 66 to 96 years. Caregivers who experienced mental or emotional strain from helping their spouses with one or more activities of daily living had a 63 percent higher risk of dying than did non-caregivers (Schulz & Beach, 1999).

Emotional Strain

Caregiving takes a toll in mental health. Although many find satisfaction in their roles, just as common are reactions like sadness, anger, guilt, resentment, and a sense of inadequacy (Rabow et al., 2004). Here is more evidence of strain:

- A number of studies document clinical depression in one half of caregivers (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989). Those most likely to be affected are females (Yee & Schulz, 2000), persons with lower income (AARP, 2001), and those who provide more hours of intense care (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001).
- A study of women with advanced breast cancer and their caregivers found equal prevalence of depression in both groups and higher prevalence of anxiety among caregivers.



Elderly spouses strained by caring for an ailing husband or wife were 63% more likely to die than were other spouses.

Caregivers' depression and perceived burden increased as the patients' functional status declined and death approached (Grunfeld et al., 2004).

- Whitlach and colleagues (2001) report that caregivers who provide long term in-home care for impaired older persons have higher levels of depression, anger, and anxiety than age-matched controls. For many the feelings persist for up to three years after placing the relative in a long term care facility.
- The less income a caregiver has, the more stress he or she is likely to experience (AARP, 2001).
- Women provide more hours and higher levels of care. They feel that they have less choice in taking on the role compared to men. These factors increase women's risk for emotional stress and lower quality of life while caregiving (National Alliance for Caregiving & AARP, 2004).



Caregiving takes a toll in mental health. Studies commonly find that one half of caregivers are depressed.

Women provide more intense care for more hours weekly. And they tend to have less choice about being a caregiver. These factors put them at higher risk for emotional strain.

Perceived burden is the strongest predictor of caregiver anxiety and depression (Grunfeld et al., 2004).

Financial Hardship

Caregiving causes substantial economic impact for both caregivers and their employers.

Impact on Caregivers

Most respondents in a 2003 survey of a broad sample of caregivers reported that they experienced little financial strain (National Alliance for Caregiving & AARP, 2004). However, studies of caregivers for the terminally ill have documented hardship from medical expenses and lost income and benefits (Rabow et al., 2004). The evidence includes the following:

- Data from a large scale national study of persons with serious illness show a variety of impacts (Covinsky et al., 1994):
 - In 20 percent of end of life cases, a family member had to quit work or make another major life change to provide care.
 - 29 percent of families lost their major source of income.
 - 31 percent lost most or all of their savings even though they had health insurance.

- Another large national study found that substantial care needs are an important cause of the economic and other burdens imposed by terminal illness. Of 988 terminally ill persons, the 35 percent with substantial caregiving needs were more likely than the others to report financial strain (Emmanuel et al., 1999):
 - 28 percent (vs. 17 percent) spent one tenth of their household income on health care.
 - 16 percent (vs. 10 percent) had to take out a loan or mortgage or spend their savings, or a family member had to get a second job.

These patients also were significantly more likely to consider euthanasia or physician-assisted suicide. Their caregivers were significantly more likely to be depressed and to report that caregiving interfered with their lives.

- African American and Hispanic families and those with the lowest incomes were most likely to experience financial hardships (Covinsky et al., 1994; Rabow et al., 2004).

Impact on Employers

Caregiving also has a substantial impact on business:

- Caregivers of breast cancer patients reported a number of impacts on their work performance (Grunfeld et al., 2004). The changes began early in the course of the patients' decline and increased during the terminal period:
 - 76 percent missed work.
 - 53 percent reduced their work hours.
 - 53 percent left work for appointments and 41 percent received interrupting phone calls.
- One national study on women and caregiving highlighted conflicting demands of work and eldercare (MetLife et al., 1999):
 - 33 percent decreased their work hours; 22 percent took a leave of absence.
 - 29 percent passed up a promotion, training, or assignment.
 - 20 percent switched from full-time to part-time status, 16 percent quit, and 13 percent retired early.
- In a large national study of caregivers, nearly six in ten reported that they worked while they were actively providing care.



Families of persons with terminal illness who need substantial daily care are most likely to report financial hardship. African American, Hispanic, and low income families are especially at risk.

Nearly 60 percent of caregivers work while providing care. Of these, 50% - 60% adjust their work schedules or reduce their hours. These changes are costly for employers.

- Of these, 62 percent had to adjust their work schedules to accommodate their caregiving responsibilities.
 - More than half (57 percent) had to arrive late, leave early, or take time off during the workday to provide care (National Alliance for Caregiving & AARP, 2004).
- Annual costs for employers are estimated at \$7.7 billion nationwide for covering caregivers' absenteeism and disrupted workdays and for replacing caregivers who quit their jobs (Metropolitan Life Insurance Company & National Alliance for Caregiving, 1997).

Caregiver Needs for Support

Based upon input from Michigan hospice contacts and from national research, caregivers' needs for support include:

- Communicating with health professionals;
- Practical training in caregiving tasks;
- Protection for vulnerable caregivers;
- Services to supplement caregiver efforts; and
- Grief support during and after caregiving.

Recently the Hospice Institute of the Florida Suncoast conducted the first nationwide study of current and bereaved end-of-life caregivers (Salmon, Deming, Kwak, Acquaviva, & Egan, 2003).

- On average the caregivers were in their early 60's and provided 87 hours of care a week for seven months.
- Their care recipients were in their 70's on average and needed help with five out of six activities of daily living.
- Most care was provided at home.

As part of the study, caregivers identified tasks that were very important to them and indicated whether or not they felt comfortable with the tasks. Table 7.1 shows their input on the top eight tasks and the paragraphs that follow provide more detail about needs for caregiver support.

Task	% Rating Task as Important	% That Feel Comfortable w/ the Task
Understanding illness	90	74
Giving medications	87	75
Knowing what to expect at time of death	84	47
Making decisions about end of life	78	54
Feeling closure	77	60
Communicating with health professionals	72	70
Giving hands on care	71	63
Finding positive aspects of caregiving	62	52

Communicating with Health Professionals

Three of the six most important tasks represent various aspects of communicating with health professionals: understanding illness, making decisions about end of life, and communicating with health professionals. Other studies reinforce this need:

- Caregivers who participated in a focus group for the New Hampshire End of Life Project indicated a preference for an honest prognosis, clear information about what to expect as the disease progresses, advice about how to handle the situation, and control over treatment decisions (New Hampshire End of Life Project, n.d.).
- A national survey on long term care from the caregiver's perspective probed their relationship with the formal health care system (Donelan et al., 2002). Findings revealed that for many the system is hard to understand and access. For some it is quite threatening. It is important to prepare caregivers to manage care, navigate the health care system, and advocate for patient care (Gould, 2004). Caregivers receive little guidance in the skills and strategies required to master these roles.

Practical Training in Caregiving Tasks

The Florida study found that caregivers value practical information about caregiving. The tasks they identified as important include giving medications, knowing what to expect at the time of death, and giving hands on care. Caregivers felt least comfortable with knowing what to expect at the time of death (47 percent) and giving hands on care (63 percent). Feeling comfortable with caregiving tasks and receiving support were associated with

reduced burden (Salmon et al., 2003). Other studies add evidence of caregiver's need for practical training:

- New Hampshire caregivers emphasized their need for technical training for caregiving responsibilities. They wanted to know how to handle feeding tubes and other treatments. They also wanted advice about how to manage emergencies and assurance that help would be timely when needed (New Hampshire End of Life Project, n.d.).
- Donelan and colleagues (2002) found that caregivers provide intense care with little or no paid help. Hospital stays for the care recipient are key events for caregivers, because the recipient needs more intense care afterward. The survey revealed that:
 - Many caregivers are not receiving adequate training to prepare them for home care responsibilities, and
 - Discharge planners are not helping them set up needed home health services for the post-acute period (Gould, 2004).
- Naylor and colleagues (1999) followed older patients during a hospital stay and at home afterward. They found that until the current hospital stay, very few caregivers had helped to lift a sick relative, get him out of bed, or help him walk. Half of them had provided no help at all to their relative prior to the hospital stay. Family caregivers provide unassisted care that requires more clinical skills than should be expected of lay people (Mezey, 2004).
- With shorter hospital stays and reduced coverage for home health services, families have to take on clinical tasks that were previously performed by health care personnel (Zarit, 2004). This may include working with medication pumps, bladder catheters, wound care regimens, and high-tech equipment. Being responsible for medical treatments and technology intimidates families and increases their anxiety. According to one ethicist, users of word processing software often get more psychosocial support than the recipients of high-tech home care (Aras & Dubler, 1994).

Several Michigan hospice contacts noted that families are not prepared for the caregiving role. One commented:



Caregivers need training in many skills:

- Talking with doctors about prognosis and treatment choices.
- Navigating a confusing and threatening health care system.
- Performing basic care and clinical tasks.

Families are not informed, they don't know what's going on with the patient, and they don't know when to say when. They don't know how to care for the person.

A Michigan stakeholder noted that while many people wish to die at home, their families are not prepared for the realities of this. Without hospice, they do not know what to expect and are not adequately prepared to provide care:

The pain and symptoms associated with end of life are shocking for families. It is scary to be totally responsible for the person's care and comfort, and there may be family discord about what to do for alarming symptoms. Families also wear out from their caregiving duties. In these scenarios, the answer is often to call 911 for help.

There are two pivotal nursing functions that support caregiver physical and mental well-being. One is helping family members deliver palliative and end of life care. The other is being present when the relative dies. The nurse's vital role at death is to help family members achieve a sense of closure about the care they gave to a dying relative. Those who feel they have fallen short experience a great deal of mental anguish. They relive the experience, focused upon what they should have done differently. This often continues long after the death. The nurse's presence and words can position caregivers to regain their physical and mental health once their loved one has died (Mezey, 2004).

Protection for Vulnerable Caregivers

Two large national studies of representative samples of informal caregivers have reached the same conclusions (National Alliance for Caregiving and AARP, 2004; Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002):

- About one third of family caregivers are vulnerable themselves.
- These high risk caregivers tend to be 65 or older, female, and caring for an elderly spouse.
- They report only fair to poor health. One third of them report that their physical health has declined since becoming a caregiver.
- They are more likely to provide high intensity care and to have difficulty with it (52 percent have difficulty). High intensity means helping with more activities for more hours (20+) per week.



Hospital stays are key events. They trigger a need for intense care afterward.

For one half of caregivers, it is the first time they have helped a sick relative. They do not know how to care for the person.

An added challenge is the need to perform clinical tasks that health care personnel used to do. Now short hospital stays have shifted the duties to family caregivers. Yet many receive no training.

- Despite their heavier burden, nearly 80 percent provide care without formal assistance. They are no more likely to have paid help than any other caregiver.

A third study found that elderly spouses who perceive strain in their caregiving role have a 63 percent greater risk of mortality than do non-caregivers (Schulz & Beach, 1999).

Input from Hospice Contacts

These vulnerable caregivers place themselves and their partners at risk for illness and injury, but many have nowhere to turn. Their plight concerns Michigan hospice providers:

- Thirty-nine percent of hospice contacts from rural and urban counties all over the state commented on the lack of support services for patients and caregivers.
 - Of the 37 mentions of this issue, 18 concerned the problem of hospice patients that have no able or available caregiver. Often these individuals cannot afford to pay for extra help at home or for care in a nursing home.
 - When an elderly spouse is present, she often does not want to put her husband in a nursing home.
 - Hospice providers in northern Michigan and the Upper Peninsula noted that often these couples have no nearby family support system. Or they have working children who cannot provide 24-hour care.
 - Patients who live alone or have a frail caregiver often need help getting up in the morning and getting ready for bed. One hospice director sends a home health aide twice a day to assist. The problem is that there are four aides and 30 patients who need help, all at the same times of day. Some of the aides begin work at 6:00 a.m. to fit in everyone.
- Another eight comments related to people “in the gap.” The hospice director focus group identified this as the number one end of life need in Michigan.
 - People in the gap do not qualify for hospice or home care but have the same intensity of need for services.
 - They commonly are declining with a slowly progressive illness and difficult-to-predict lifespan. They cannot afford private help or nursing homes.



One third of caregivers are in a precarious position. They provide intense and continuing care to others while they suffer from poor health themselves.

- People in the gap may be hidden to the helping community. They intersect with the health care system through physician visits and the occasional hospital stay.
- They may receive home health care after a hospital stay, but service must be discontinued once acute treatment goals are achieved.

It is difficult to identify and quantify the number of caregivers who need support and to determine the extent of their need. Often they are exhausted by the time they connect with hospice. This fact suggests a lengthy prior period of unsupported caregiving and a significant level of unmet need.

One set of researchers documented the types of assistance provided by 151 family caregivers for terminally ill cancer patients (Brazil, Bedard, Willison, & Hode, 2003):

- These are functional activities and the percentage of caregivers that helped with them:
 - Bathing (88 percent) and dressing/undressing (76 percent);
 - Mobility (81 percent) and toileting (76 percent);
 - Assistance at night (64 percent).
- A full 41 percent of caregivers had provided some form of care for more than one year. Caregivers reported that the physical demands of caregiving increased significantly during the three months before death. Family caregivers who provided more assistance with ADLs were more likely to report high burden.

Services to Supplement Caregiver Efforts

Caregivers need an array of services to remain healthy, develop their caregiving skills, and remain in the caregiving role:

- Support services may include information, counseling, support groups, respite, and home modifications or assistive devices.
- They are available most often through local government agencies and service or faith-based organizations.
- Some employers are beginning to implement workplace programs to support their caregiving employees (Family Caregiver Alliance, 2003).
- Hispanic (80 percent), African American (75 percent), and Asian American (73 percent) caregivers are more likely to



Support services for family caregivers are in short supply in Michigan. This is especially a problem for people “in the gap.” They have intense needs but do not qualify for home care or hospice. And they lack the means to hire extra help or pay for a nursing home.

Four of ten caregivers provide care for more than a year before a terminally ill person dies. Physical demands increase during the final three months. Many are exhausted by the time they connect with hospice.

report unmet needs than are white caregivers (64 percent) (National Alliance for Caregiving & AARP, 2004).

Support services can make a difference in caregivers' day-to-day lives. For example:

- There is a significant body of research evidence showing that respite can ease the emotional distress associated with caregiving (Silverberg, 2001).
- Research has found that counseling and support groups can be effective when combined with respite and other services. The support helps caregivers remain in their roles longer with less stress and greater satisfaction (Family Caregiver Alliance, 2003).
- Women are more than twice as likely as men to say that they would gain from talking to someone about their caregiving experience (National Alliance for Caregiving & AARP, 1997).

Not surprisingly, some researchers report that programs that link people to services are more helpful than programs that provide information only (Whittier, Coon, & Aaker, 2002).

Input from Hospice Contacts

Michigan hospice providers are united in their recognition of the need for caregiver support and the lack of available services. These are the issues they raised:

- There are limited options for respite care.
 - Current services are understaffed and under-funded. Many have waiting lists, and some are too expensive. Some older persons are reluctant to accept services in their homes from strangers.
 - There is a need for more hospice residences and units to help with respite care.
- There is a general lack of support services for caregivers.
 - This concern was raised by hospice contacts in every area of the state.
 - Where services ARE available, they are unaffordable for most people.

Many hospice providers, hospitals, and Area Agencies on Aging have offered caregiver support groups at one time or another. A



Support programs that link caregivers to services are more useful than those that provide information only.

number have given up on this approach, since participation is low. Even offers of free in-home respite support have not attracted caregivers. The perception is that they are too busy and reluctant to leave their loved ones alone. One hospice contact has found that a casual gathering for a cup of coffee at a fast food restaurant attracts more people than a meeting in a more formal setting.

Grief Support During and After Caregiving

The experience of caring for loved ones as they approach death can be rewarding, but it is also traumatic. Grief and loss are inherent in the process (Doka, 2003). Family members begin to grieve as soon as they acknowledge an impending loss. They continue to mourn through the caregiving period and finally work through their grief after the death happens (Connor, 1997). Clinicians should view bereavement as a phenomenon that affects caregivers both before and after the loved one's death (Schulz et al., 2003).

Whenever it occurs, grief threatens health. It has been associated with poor outcomes including depression, insomnia, substance abuse, suicide attempts, and mortality (Connor, 1997; Rabow et al., 2004). Research suggests that caregiving experiences of family members can influence their adjustment to the person's death. Schulz and colleagues (2001) reported that strained elderly caregivers had high levels of depressive symptoms during caregiving and maintained their distress during the year following the spouse's death.

There is a growing body of evidence suggesting that grief support can prevent or reduce problems:

- Spouses who cared for a loved one before death and received hospice support before, during, and after the death seemed to have fewer health complaints (Connor, 1997).
- When physicians listened to needs and opinions of caregivers of terminally ill patients, those caregivers benefited. They had significantly less depression (27.6 percent) than did caregivers of similar patients with less empathic physicians (42 percent) (Emanuel, Fairclough, Slutsman, & Emanuel, 2000).
- A study of 73 adult family caregivers found that support during caregiving had a larger impact on post-death adjustment than did bereavement support. Caregiving support accounted for 29 percent of the variance in



Grief and loss are inherent in caregiving. Support during the process has a major impact on post-death adjustment.

Factors that interfere with grieving include:

- Prolonged caregiving during a lengthy illness
- Distress about the decedent's suffering
- Anguish about difficult treatment decisions.

"How people die remains in the memories of those who live on."

--Dame Cicely Saunders

outcomes, compared to 2 percent for grief support (Bass, Bowman, & Noelker, 1991).

According to Rando (1993, p.9), it is well documented that survivors are at risk for problems in mourning when a loved one's illness is lengthy. Doka (2003) identifies these reasons:

- Prolonged caregiving is draining. It saps the caregiver's energy for dealing with bereavement.
- Other equally affected family members may be less available to support the primary caregiver.
- The stress of caregiving can fray relationships by creating or intensifying family conflict.
- Survivors may be troubled by the extent that the decedent suffered.

Grief may be especially complicated when the end stages of chronic disease require family caregivers to make difficult ethical decisions about treatment. Those experiences can haunt survivors for some time and interfere with their healthy adjustment to the loss. Dame Cicely Saunders, founder of the hospice movement in England, has said that "how people die remains in the memories of those who live on" (as cited in Rabow et al., 2004).

Identifying high risk caregivers and supporting them through caregiving and bereavement are important steps to prevent excess morbidity and mortality among family survivors.



Identifying high risk caregivers and supporting them through caregiving and bereavement are key steps to prevent excess morbidity and mortality among family survivors.

Obstacles to Improvement

Policy Obstacles

Family members are assuming increasing responsibility for the care of their sick relatives. While caregiver support is an emerging policy concern, there is little evidence that it is yet a federal, state, or local priority (Mezey, 2004). This reality is validated by hospice contacts' observations that respite services are in short supply.

System Obstacles

Hospitalization triggers a need for caregiving, often for the first time. But families do not receive the coaching they need to prepare for their new caregiving responsibilities.

- With shortened stays, sicker patients, and fewer nurses, it is difficult for hospital nurses to adequately teach family

members to provide care the patient will need when discharged. As a result:

- 57 percent of caregivers received no coaching about how to safely help the patient with activities of daily living;
 - 31 percent received no training in required dressing changes; and
 - 18 percent received no instruction in the use of medical equipment (Gould, 2004).
- Reimbursement for home care also makes it increasingly unlikely that the home care nurse has time to teach and observe the caregiving skills of family members (Mezey, 2004).

Hudson, Aranda, and Kristjanson (2004) have identified a number of other health system barriers that make it difficult to offer caregiver support:

- Clinical professionals may lack the time and skills to develop and carry out interventions for caregiver education and support.
- There is a paucity of print and video resources available for caregiver education.
- Lack of continuity among providers and care settings can disrupt attempts to educate and support caregivers.

Provider Obstacles

Providers lack data and tested interventions to guide their efforts to help family caregivers. This is especially true for providers of end of life care. Most of the literature on family caregiving focuses on persons with frailty and dementia, rather than on care of persons with advanced illness at the end of life (Lorenz, 2004b). Below are examples of the state of research in caregiver support:

- The extent of burden for caregivers has just been documented in recent years. As a result, providers are only beginning to develop and test interventions to assess and support caregivers' needs. There are a limited number of investigators doing this work. They have tried both education and support, but it is not yet clear which approach works for which caregivers (McMillan, 2004).
- A first step toward reducing caregiver burden is to assess the extent of burden and needs for support. As yet there is



Clinical professionals lack the time and skills to educate family caregivers.

There is a lack of proven methods for assessing caregiver risk, teaching them skills, and supporting their needs. Individual attention and respite care seem to be most effective.

Caregivers' ability to learn may be limited by the stress they feel.

no consensus on the approach and tools for such an assessment (Feinberg, 2002). A few studies have identified caregivers with the greatest risk for distress, but few have tested the impact of interventions for these high risk persons.

- Interventions to relieve burden have been tested mainly for caregivers of persons with dementia or terminal cancer.
 - Investigators have tried both individual and group approaches. These include education, counseling, support groups, home health, hospice, and palliative care services. Results have been inconsistent.
 - Individual approaches seem to be most effective, although group interventions are more common. Only multifaceted interventions and some respite services have shown small positive impacts on caregiver burden (Lorenz et al., 2004).

- Systematic reviews of interventions for family caregivers have concluded that most efforts had no large effect on relieving burden. Some reviews identified small but significant gains for caregivers via education, respite, and caregiver support (Lorenz, 2004a).

- A survey of 200 hospice training directors around the country revealed that hospices need practical ideas for developing effective caregiver training programs. The needs were the same without regard to hospice size or region of the country. For their current training efforts:
 - 54 percent do not use visual aids;
 - 61 percent lack speaker’s notes;
 - 69 percent lack information about effective training strategies and presentation skills; and
 - 90 percent do not have materials to promote the trainings and motivate caregivers to participate (Salmon et al., 2003).

Michigan hospices, hospitals, and Area Agencies on Aging offer caregiver seminars, lecture series, how-to classes, and support groups. Many hospice contacts said that they have discontinued support groups because of low or no participation. Even offers of free respite care have not improved attendance.

Consumer Obstacles

Hudson et al. (2004) examine several reasons why caregivers may not take advantage of support services:

- Difficult family dynamics or incongruent patient and caregiver needs for information may interfere.
- Caregivers' ability to absorb and act on new information may be compromised by the stress they feel.
- Caregivers may be reluctant to "bother" health care professionals for information.

Hospice contacts commented that caregivers may not attend support groups because they feel reluctant or unable to leave their loved one or disinclined to leave a stranger alone with him or her. It also may be difficult for a caregiver to commit to a scheduled time, not knowing what may be happening then with the care recipient.



Hospices need practical ideas for effective caregiver training and support. There are a number of promising innovations, both nationally and in Michigan.

Encouraging Factors

Hospice Model

Hospice IS caregiver support. The hospice model of care is person-centered, and the patient and family together are the unit of care. Caregiver teaching and support are integral to hospice service from all team members. In addition, hospice volunteers are available for caregiver support and respite. Increasing the use of hospice will increase caregiver support.

- *Non-Hospice Caregiver Training*
A recent survey of 200 hospice training directors around the country revealed that 14 percent of them offer caregiver training for non-hospice caregivers as a service to the community. Another 25 percent valued the idea but had not yet tried it (Salmon et al., 2003).
- *Caregiver Resource Center*
Hospices can offer an essential service by providing support, education, and resources for caregivers in the community. Many of the families served will choose hospice when the time is right. But they need support and services before hospice is offered. Hospice agencies can fill an unmet need and help community caregivers feel the benefit of hospice support (Salmon et al., 2003).

Innovative Programs

There are a number of promising program models to address caregiver needs, both nationally and in Michigan.

National Models

Four examples of successful programs are California's Caregiver Resource Centers, Florida's Caregiving at Life's End Program, Fannie Mae's Elder Care Initiative, and Oregon's Lifespan Respite Program.

- Caregiver Resource Centers (CRC)—California funds a network of resource centers for caregivers of adults with cognitive impairment. The CRCs provide information and referral, assessment and care planning, counseling, support groups, caregiver education, legal help, and a wide range of respite choices. A consultant provides technical assistance to the centers and manages a clearinghouse and data support (Silberberg, 2001).
- Caregiving near Life's End—This is a caregiver training and public engagement program (Caregiving near Life's End, 2004). It was developed by The Hospice Institute of the Florida Suncoast in response to findings from a national assessment of caregiver needs. The developers train others to use the program. At least two Michigan hospices have a trainer on staff. Caregiving near Life's End:
 - Includes a caregiver training curriculum that focuses on the experience and purpose of caregiving; and
 - Teaches trainers to assess caregiver needs in a community, develop a network of organizations to offer services, and recruit volunteers to provide support for caregivers.
- Fannie Mae Elder Care Initiative—This program was launched in 2001 to support employees who also are family caregivers in end of life situations. The program includes:
 - A full-time onsite case manager contracted through a local senior service agency. She provides counseling and referrals to employees.
 - The Elder Care Tool Kit, a resource guide for caregivers.
 - Flexible Work Options, a program that enables employees to adjust their work schedules to accommodate their caregiving responsibilities.

Elder Care program costs are low and employee morale, productivity, and retention are high. Employees are exceptionally pleased with the Initiative. Of those who have used it, 28 percent said that without the support they would have had to quit their jobs.

- Oregon Lifespan Respite Program—Launched in 1997, this program promotes the creation of community-based networks that facilitate access to respite for all caregivers who provide ongoing care to any person with special needs. The state provides technical assistance plus start-up and annual funding to local networks. They raise additional funds through grants and donations. Each network recruits and screens respite care providers, helps clients define their needs, and connects them with services and payment options. Several other states have adapted this program (Silberberg, 2001).

Michigan Innovations

A number of hospices have developed creative approaches to support the caregivers in their areas. They are ideas that other agencies can adopt. These are three examples:

- Volunteer Mentors—Extensively trained volunteers visit caregivers at home to provide one-on-one training in patient care tasks. Examples include turning and positioning a person in bed, transferring from bed to chair and back, providing mouth care, toileting, and changing incontinence briefs.
- 16-Hour Respite—Each family can use up to 16 hours of respite care per week. The care is provided by a private duty home health aide; the cost is paid through hospice donations. The aide is available any day and any time. The hours may be used consecutively or in chunks. About 60 percent of families use at least some of their hours each week, usually during the day. Caregivers use the respite support to take a break, run errands, or even work part time.
- Overnight Respite—At least one hospice has volunteers who are willing to stay overnight. This allows family members to get an uninterrupted night's rest while the volunteer cares for the hospice patient.

Useful Resources

Among the resources available for caregiver education in Michigan are these two programs.

Alzheimer's Association Family Caregiver Training

This three-part series is especially tailored for caregivers of persons with Alzheimer's disease, Parkinson's disease, or Huntington's disease.

American Red Cross Family Caregiving Program

This new collection of nine 1-hour videos includes modules on positioning and mobility, helping with personal care, caring for a person with dementia, safety, and caring for the caregiver. The Washtenaw County chapter is one of the first to offer the program in Michigan. In that area, the modules also are presented through hospitals and other community agencies. Home study is possible with a participant booklet. There may be a nominal fee. Not all Red Cross chapters offer this resource.

Clergy End-of-Life Project

The Florida Department of Elder Affairs and the Hospice Foundation of America sponsored a project to develop a guide to help clergy support families at the end of life. The guide is used by regional trainers to educate clergy in communities statewide.

TLC in the Workplace

The National Hospice and Palliative Care Organization (NHPCO) has developed this program for human resource professionals and managers. It is intended to help the support employees who are coping with caregiving, grieving a personal loss, or critical incidents at work. The program includes a toolkit and curriculum for a 4-hour training session. NHPCO developers offer a train-the-trainer course to prepare hospice contacts to educate employers.

Implications for Policy and Programs

Death from chronic disease is often preceded by a lengthy period of family caregiving. Families provide about 80 percent of the personal care required by the elderly. This is true even for the severely impaired who have functional limits and care needs identical to those of the nursing home population (Albert, 2000).

The intensity of care increases as the end of life nears. With changes in health care financing, families have taken on clinical

tasks that were previously performed by medical personnel. A large body of literature has documented the strains on mental, physical, and financial health that accompany caregiving. Physicians and other health care providers need to be alert to these risks and take action to address caregivers' needs.

Train Caregivers

Relying on caregivers without considering their ability to provide care is unwise and unsafe. Most are novices, unprepared for their responsibilities. They need training to assist with activities of daily living, to perform medical tasks, and to navigate the health care system. The importance of caregiver learning needs has received minimal attention from health care providers and systems. Although interventions are still being refined and tested, Michigan providers should adopt and evaluate promising approaches now.

Since many caregiving needs arise for the first time after a hospital stay, hospitals should assess and train caregivers as part of discharge planning. Home care and hospice providers should assess caregiver needs and risk with each admission and take action as necessary. The MDCH should collaborate with appropriate partners to explore feasible options for assessing and training high risk caregivers in a variety of health care settings.

Increase Access to Support Services

One third of caregivers are themselves vulnerable due to old age and poor health. It should be a priority for providers to identify these individuals and arrange support services to assist them. These caregivers can be identified when the care recipient is admitted for service, but also when a patient is discharged from service. Home care providers in particular know when they are discharging an elderly couple into "the gap." Their needs should be anticipated and support services arranged well before discharge.

Respite care is a critical service for caregivers of persons with advanced illness and persons at the end of life. Given resource constraints in Michigan government, the only reasonable solution may be to rely on community action. According to Emanuel and colleagues (1999), the amount of volunteer help provided to terminally ill persons by communities is negligible.

Doka (2003/2004) notes that caregivers may need to know about services to realize the need for them. Faith communities may be a key conduit to information and services:

- They are a credible local presence.



Michigan should take these steps to support family caregivers:

- Explore options for assessing and training high risk caregivers in a variety of health care settings
- Explore options for expanding caregiver support services through community partners
- Monitor outcomes of efforts and share best practices statewide

- Services they sponsor or provide may be more readily accepted than the same services offered through less familiar agencies.
- Connecting members to help one another through respite or other support services is an appropriate ministry for a congregation.
- Clergy, pastoral care workers, and parish nurses can offer their presence to help families cope with spiritual needs that arise during caregiving.

It would be appropriate for the MDCH to take these steps to expand access to support services for end of life caregivers:

- Convene appropriate state and community partners to:
 - Ensure that Michigan respite policy and resources meet the needs of caregivers for persons nearing the end of life;
 - Explore collaborative opportunities to expand respite and other services for high risk caregivers through faith communities;
 - Examine the value and feasibility of piloting caregiver resource centers for communities, perhaps housed at hospice agencies;
 - Promote interventions to ensure informed choice and appropriate pain and symptom control to reduce caregivers' anguish about their loved ones' care; and
 - Alert employers and employee assistance programs about worksite options and resources for support of employee caregivers.
- Provide technical assistance to MHPCO to:
 - Help hospice providers share and adopt promising innovations like volunteer mentors, respite options, and the Caregiving Near Life's End intervention.
 - Assess hospice providers' need for and interest in training in skills to bolster the effectiveness of their community education programs.

Reliance on family caregivers is likely to grow in the future as efforts to manage health care costs continue. As the population ages in coming decades, sustaining informal caregiving may be more challenging. There will be more individuals who need care and they and their caregivers are likely to be older and more vulnerable. The support services that society is slow to develop now will be even more critical soon. The MDCH should spearhead action to ensure that Michigan is poised to meet the need.

Key Points

Death from chronic disease is often preceded by a lengthy period of decline. Families provide about 80 percent of the personal care required during this time.

About 1.2 million Michigan residents provide informal care for persons aged 50 and older. An estimated 120,000 of them are at high risk for physical, emotional, and financial strain.

More than one third of persons with terminal illness need substantial help daily. Caregivers usually have no training in moving, lifting, or turning seriously ill adults. About one third of those who perform these strenuous tasks are older and in poor health themselves. Caregiving can be lethal for the elderly.

Nearly 60 percent of caregivers are employed. Of these, 50 to 60 percent adjust their work schedules or reduce their hours. Others have to leave their jobs. These changes are costly for employers.

Hospital stays are key events. They trigger a need for intense care afterward, often for the first time. One half of caregivers have never helped a sick person, yet most receive no training.

An added challenge is performing clinical tasks that health care personnel usually do. Short hospital stays have shifted the duties to family caregivers after discharge. Yet clinical professionals lack the time and skills to train them.

Support services for family caregivers are in short supply in Michigan. This is especially a problem for people “in the gap.” They have intense needs but do not qualify for home care or hospice. They also lack the means to hire extra help or pay for a nursing home.

Grief and loss are inherent in caregiving. Support during the process has a major impact on post-death adjustment. Caregiving during a lengthy illness, distress about suffering, and anguish about treatment decisions all interfere with a caregiver’s healthy grieving.

Identifying and supporting high risk caregivers are key steps to prevent excess morbidity and mortality among family survivors.

Reliance on family caregivers is likely to grow. As the population ages, both care recipients and providers will be older and more vulnerable. The MDCH should convene partners now to expand services for caregiver assessment, training, respite, and other support.