

2

Contents of Section

Patterns of Decline

Michigan Stakeholder Views

National Views

Michigan Policy

Implications for Policy and Programs

Key Points

Defining End of Life

The beginning of the end of life is not easily delimited. But defining end of life is a necessary first step toward assuring that related needs are recognized and addressed. Nationally, the conceptual model of terminal illness has shaped programs and policy. It is driven by the Medicare rule that a person must have a six-month-or-less prognosis to be eligible for the hospice benefit. State Medicaid programs (including Michigan's) that offer a hospice benefit carry the same eligibility requirement. But death is not that easily predictable for most people.

Patterns of Decline at the End of Life

Research scientists at the National Institutes of Health have mapped four patterns of decline in the final year of life that account for 76% of deaths among the elderly. Timing of death was unpredictable except in the cancer group (Lunney et al, 2003). The four patterns of terminal decline include:

1. *Sudden death* with no functional decline (15%).
2. *Expected death* from cancer with a short period of decline (21%).
3. *Entry-reentry death* from a serious chronic illness (20%). These people experience multiple hospital stays due to a series of exacerbations, any of which may lead to sudden death from organ failure.
4. *Lingering death* associated with dementia or frailty in old age (20%). These people were the oldest and most disabled, typically living in nursing homes.

Michigan Stakeholder Views

Of the 29 Michigan stakeholders who commented upon how to conceptualize end of life for policy and program purposes, 80% chose a broad view.

- 17% defined end of life to include only the terminally ill who are eligible for hospice and approaching death.
- 50% included the terminally ill plus persons in advanced stages of a life-limiting illness.
- 30% included the above two groups plus people declining with frailty of old age.
- 3% were not sure which groups to include.
- Two persons (7%) added that end of life policy and programs also should include families whose loved ones die suddenly.

The stakeholders who limited end of life to terminal illness framed end of life as a short-term process or sudden event. To define it they looked to eligibility criteria for the Medicare or Medicaid hospice benefit.

Those who preferred a broader definition for end of life framed it as a period of transition and spoke about it in terms of common needs for decision-making and symptom management well before the very final days:

Typically end of life means actively dying, but we've missed the boat if that's our definition. EOL is the period when you realize that with the constellation of physical conditions related to aging and mental conditions related to the diseases, a person is starting down his/her final path. Then is the time to start decision-making with the patient and the people who are important to him, even though you don't know exactly what his path will look like or how long he will be on it.

Anyone in the throes of functional decline in any long term care setting should come under the end-of-life umbrella. They face the struggles of deciding how and where to spend the rest of their lives and how to plan and navigate the continuum of care.



All groups should be included in policies and programs related to end of life—terminally ill, advanced chronic illness, advanced frailty and functional decline, sudden death. In fact, the greatest gaps in service are for those who do not meet hospice eligibility requirements.

All groups should be included in policies and programs related to end of life—terminally ill, advanced chronic illness, advanced frailty and functional decline, sudden death. In fact, the greatest gaps in service are for those who do not meet hospice eligibility requirements.

We have developed an algorithm that identifies terminal illness, advanced chronic illness, and decline due to age-driven or disease-driven frailty as prompts for physicians to begin a dialogue with patients for end of life planning.

People at earlier stages of chronic disease deserve and need the services now provided only to patients who are dying. They live in as much need even with death not imminent, and they need hospice-like services to ensure quality of life. If defined purely by need, end of life would include people with terminal illness, people declining with advanced stages of a life-limiting illness, and people declining with the frailty and functional dependence of advanced age.

National Views

While national policy has not yet changed, national work groups have begun to adopt broader definitions of end of life.

American Geriatrics Society

In a 1997 statement of principles for quality care at the end of life, the American Geriatrics Society defined people as dying when they have “progressive illness that is expected to end in death and for which there is no treatment that can substantially alter the outcome” (AGS, 1997).

Institute of Medicine (IOM)

Members of the IOM Committee on Care at the End of Life noted that the terms incurable, terminal, or fatal illness as commonly used include people with advanced progressive conditions whose deaths are difficult to predict and might not come for years (IOM, 1997).

Similarly the report *Describing Death in America*, issued by the IOM National Research Council in 2003, defines end of life broadly. It includes “the period during which an individual copes

with declining health from an ultimately terminal illness, from a serious through perhaps chronic illness, or from the frailties associated with advanced age—even if death is not clearly imminent” (IOM, 2003).

Centers for Disease Control and Prevention (CDC)

When research scientists at the CDC launched an end of life project in 2002, they purposefully conceptualized end of life broadly enough to include seriously ill, injured, or dying people of all ages and their families (Rao, 2004).

Michigan Policy

Michigan has taken important steps to establish a broad definition of end of life for policies and programs in the state.

Michigan Commission on End of Life Care

In 1999 an Executive Order created the Michigan Commission on End of Life Care within the Michigan Department of Community Health (MDCH). The group was directed to study and recommend changes for improving end of life care in the state. The Commission did not specifically define end of life, but members did conceptualize it more broadly than terminal illness. The six general principles that they set forth to guide public policy cite the importance of addressing the needs of persons of all ages who live with life-limiting or life-threatening conditions or advanced severe illness. (Michigan Commission on End of Life Care, 2002).

Amendment of the Michigan Dignified Death Act

The Michigan Dignified Death Act, Part 56a of the Public Health Code, was passed in 1996. It protects people’s right to choose or refuse curative treatment and to receive palliative treatment for pain and other distressing symptoms. The Act requires physicians to inform terminally ill patients about the following:

- Treatment choices;
- Their right to designate a patient advocate; and
- Their right to make informed decisions about medical care.

In the statute terminal illness had been defined as having a six-month-or-less prognosis. This “six-month rule” is widely regarded as a barrier to access to the Medicare and Medicaid hospice benefits. Based upon the Commission’s recommendations, the

Medicare Six-Month Rule

The Medicare six-month rule was developed in the 1970’s based upon research findings that the majority of cancer patients died within six months after diagnosis. The rule was intended to control expenditures for the program by restricting access to the hospice benefit to those very close to death, as opposed to those who are chronically ill with death not imminent.

The six-month rule has indeed limited access to hospice, particularly after auditors from the United States Office of the Inspector General in the mid-1990’s scrutinized physicians and hospices when patients lived longer than six months. Physicians find it difficult to estimate a precise time to death, particularly for persons with non-cancer diagnoses for which death is less predictable. And just as doctors often find it difficult to communicate a terminal prognosis, patients and families find it difficult to hear and to accept. They also may be reluctant to waive possibly curative treatment, even with little chance of success, to accept hospice care.

As a result of factors like these, lengths of stay in hospice are brief. The Michigan Hospice and Palliative Care Organization reports a median length of stay of 20 days for 2002.

state legislature in 2001 amended the Michigan Dignified Death Act to eliminate references to terminal illness. Those words were replaced with the phrase “reduced life expectancy due to advanced illness.”

Eliminating references to terminal illness from state statutes does not affect federal Medicare rules, and it has not changed Michigan Medicaid rules. But removing the six-month roadblock was regarded as a significant policy step toward improving access to hospice care and humane treatment for state residents who are living and dying with advanced illness and severe pain (Senate Fiscal Agency, 2002).

Implications for Policy and Programs

It is not easy to identify an exact starting point for the end of life phase. Some people die suddenly, some expectedly after a brief period of decline, and many unpredictably after dwindling through years of ups and downs. For decades national policy has defined end of life as the final six months of a terminal illness. That policy has contributed to late or no access to supportive services for many dying persons.

Michigan stakeholders view end of life more broadly than terminal illness, because people with late-stage disease have many needs similar to those for whom death is imminent. Michigan law now protects the right to informed choice and palliative care for any person with reduced life expectancy due to advanced illness.

Key Points

National policy defines end of life as the final six months of a terminal illness. This is based upon the Medicare requirement for a six-month-or-less prognosis to access the hospice benefit.

In the last seven years, national policy work groups have defined end of life more broadly. They include the period of decline from an advanced progressive illness that will ultimately end in death, even though timing may be unpredictable.

The Michigan Dignified Death Act conceptualizes end of life broadly to include persons with reduced life expectancy due to an advanced illness. Michigan Medicaid policy defines end of life narrowly as terminal illness with a six-month-or-less prognosis.

Most Michigan stakeholders view end of life as encompassing advanced stages of life-limiting illness and functional decline, when there are common needs for decision-making and symptom management well before the final days.