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Critical End of Life Need #1: Eliminate Unnecessary Suffering

End of life in Michigan is marked by unnecessary suffering, by lack of informed choice, and by inadequate caregiver support. These are serious problems. They surface in all regions and care settings in the state and in all ages and ethnic groups. They apply to many people who die from accidents and trauma and to people who die from chronic diseases. These problems are magnified in underserved population groups.

Michigan ranks among the states that have been most actively involved over the past decade in efforts to improve health care and quality of life at the end of life. There is growing recognition of the need for improvement as the aged population expands. Concern intensifies as more opinion leaders have personal experiences with relatives and friends in their final days. There is activity on a variety of fronts, driven mainly by individual compassion and humane commitment. Despite obstacles, much has been achieved. But there remains much more to accomplish to eliminate unnecessary suffering at the end of life.

This section reviews the extent of the problem, obstacles to improvement, encouraging factors, and implications for policy and programs.

The Extent of the Problem

Pain and symptom management to eliminate needless suffering emerged as the most pressing priority among the 107 interview contacts, named by 80 percent of them. Public testimony at September, 2000, hearings of the Michigan Commission on End of Life Care echoed this concern. Significant numbers of patients,

caregivers, and professionals cited ineffective pain management as one of the state’s most serious problems in end of life care. Noting the broad consensus, the Commission’s final report declared inadequate pain and symptom management to be “a public health issue that requires the highest level of professional and regulatory attention” (Michigan Commission on End of Life Care, 2002).

Unmanaged pain is a complex issue with challenging policy, system, provider, and consumer aspects. Even so, the need to address the problem is urgent:

- Unnecessary suffering remains widespread in Michigan.
- It is people’s greatest fear related to end of life.
- People suffer unnecessarily in hospitals, in nursing facilities, and at home.

The prevalence of needless suffering is disturbing, especially for those who see the human costs every day. One stakeholder who served on the Michigan Commission on End of Life Care commented:

The gaps in pain management across settings are still appalling, and there has been little progress in improving management of other symptoms.



End of life in Michigan is marked by: needless suffering, by lack of informed choice, and by inadequate caregiver support.

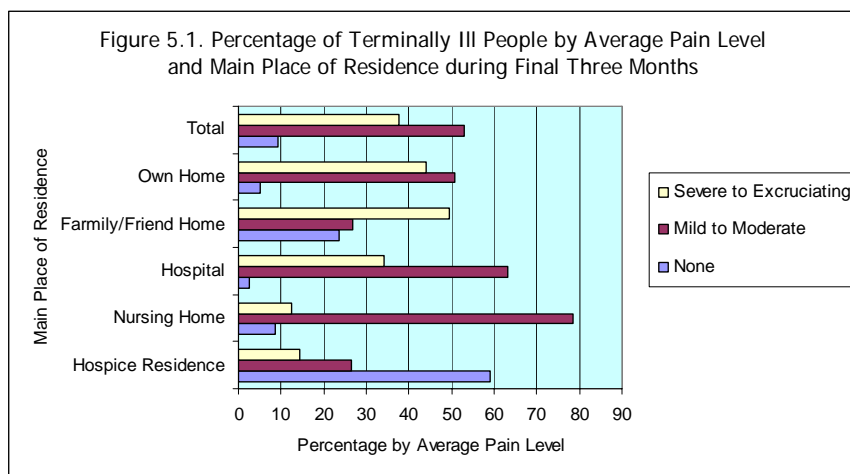
Unnecessary suffering happens in hospitals, in nursing facilities, and at home.

The need to address this critical problem is urgent.

38% of decedents suffer severe to excruciating pain during their final months.

How Many Suffer at the End of Life?

During their final three months of terminal illness, 38 percent of Michigan decedents suffered with severe to excruciating pain. This was reported by their caregivers in the 2002 Special Cancer Behavioral Risk Factor Survey BRFSS. Figure 5.1 shows the prevalence of extreme pain by place of residence.



Source: BRFSS EOL Section, Michigan Public Health Institute, 2002

Note that caregivers reported severe to excruciating pain for:

- Up to 50 percent of people who lived in private homes;
- 34 percent in hospitals; and
- 12 percent in nursing homes.

Across the state, nine of every 10 hospice contacts reported that pain management is a problem in their service areas. When asked what proportions of patients come to them with severe pain, 48 of the 57 hospice contacts (84 percent) were able to provide estimates. (Severe pain is a patient-reported rating of 6+ on a 0-10 scale, where 0 is no pain and 10 is the worst pain imaginable.) Table 5.1 summarizes their responses.

% of Patients Admitted with 6+ Pain Level	Number of Hospices	Percentage of Hospices
0% - 24%	8	17%
25% - 49%	17	35%
50% - 74%	17	35%
75% - 100%	6	13%

Fully eight of ten hospice contacts estimated that at least one quarter of their new patients are suffering with severe pain.

- Almost half estimated that 50 percent or more of their patients come to them with severe pain.

This is not a new problem in Michigan.

- In 2000, hospice directors estimated that more than 33 percent of new patients were admitted with severe or uncontrolled pain.

These are findings of a study conducted by the Michigan Hospice and Palliative Care Organization (Michigan Commission on End of Life Care, 2002).

Suffering at Home

For at least two decades, researchers have documented the prevalence of pain at the end of life in persons with cancer and other diagnoses. The Michigan estimates are congruent with their findings. Most commonly, studies report that at least 30 percent of people suffer from severe pain in their final days (Field & Cassel, 1997).

About 27 percent of Michigan residents died at home in 2002. Some researchers have studied the prevalence of pain in people who die at home:

- Community physicians who treated 182 elderly patients during their final months reported that pain greatly limited the function of 31 percent of the people. As death approached, pain became an important management issue for 48 percent of the group (Goodlin, Jette, Lynn, & Wasson, 1998).
- Among 54 cancer outpatient clinics, about one third of patients with metastatic cancer had pain that limited their function (Cleeland et al., 1994).
- Another group of researchers identified a sample of people from 22 states who died in 2000. They interviewed family members about the decedents' end of life care. Nearly one fourth of all respondents reported that the person did not receive any or enough help with pain (24.2 percent) or shortness of breath (22.4%).
 - Results were worse for those who died at home with home care. About four of every ten respondents reported that the person did not receive any or enough help with pain (42.6 percent) or shortness of breath (38 percent) (Teno et al., 2004).
- Cherney and Catane (1995) concluded that from 64 percent to 80 percent of patients admitted for hospice services had inadequately relieved pain.

Suffering in Hospitals

Almost half of Michigan deaths in 2002 happened in hospitals. In Wayne County, more than 40 percent of decedents in 1997 spent time in an intensive care unit. Intensive care rates in other areas of the state varied between 13 percent and 40 percent (Wennberg, 2000). Stakeholders described some of the interventions common

in critical care units as torture. Two critical care specialists wrote these remarks (Wood & Marik, 2004):

The technological advances that medicine has witnessed in the last few decades are no more apparent than in the ICU. Yet when used inappropriately, this technology may not save lives nor improve the quality of a life, but rather transform death into a prolonged, miserable, and undignified process.

- A landmark study in 1994 followed a large national sample of people who died in hospitals. Almost 40 percent of the conscious patients had severe shortness of breath and severe pain most of the time in their final days (Lynn, Teno, et al., 1997).
- Campbell and Guzman (2003) point out that even intensive care patients with conditions known to be nearly always fatal (like multiple organ system failure) are treated aggressively until death occurs.

Suffering in Nursing Homes

About 24 percent of Michigan deaths happened in nursing homes in 2002. Large national studies have repeatedly found that pain is not well managed in nursing facilities (Bernabei et al., 1998; Manzer, J., 2003; Teno, Bird, & Mor, n.d.):

- Consistently 1 in 4 elderly residents with daily pain—both cancer and chronic noncancer pain—receive no pain medicine at all.
- Residents with cancer who are older than 85, African American, or cognitively impaired are most likely to have untreated or under treated pain

Brown University researchers analyzed patient assessment data from Michigan nursing homes in 1999 (Brown University, n.d.; Teno, Weitzen, Wetle, & Mor, 2001).

- They found that 40.6 percent of residents with terminal illness lived with moderate or excruciating pain daily.
- In 2000 the researchers checked the persistence of pain across two assessments 60 to 180 days apart. They reported that 40.9 percent of residents with severe daily pain on the first assessment still had severe pain on the second.

- The rate of persistent pain through two assessments was even greater—45 percent—for residents with cancer.

Patient assessment data reported by all 431 Michigan nursing homes to Medicare and accessed in July, 2004, showed wide variation in assessed pain levels among facilities (Nursing Home Compare, n.d.).

- For long term residents (those with stays longer than 100 days), a statewide average of 6 percent were assessed to have daily severe pain, with a range of 0 percent to 33 percent among facilities.
- For short stay residents (those who had not reached the 100 day mark), a statewide average of 23 percent were reported to have daily severe pain, with a range of 0 percent to 60 percent across facilities.

Both the long term and short stay groups include residents with terminal illness. Variations in rates of daily pain may reflect either differences in resident population, pain assessment, pain management or any combination of these factors. A low rate of reported pain may reflect inadequate assessment, while a high rate may indicate that pain is being assessed but not treated effectively.

One stakeholder who served on the Michigan End of Life Commission noted:

Providing quality end of life services for the long term care population is a bigger need than the Commission realized. Exploding demographics have us heading toward a crisis that we are not prepared to handle.

The Consequences of Unrelieved Pain

There is significant evidence that unrelieved pain at the end of life hastens death (Paice & Fine, 2001). And in the process it exacts a high price in spiritual exhaustion and reduced quality of life. Unrelieved pain also carries a high cost for caregivers. Seeing a loved one suffer is one of the most distressing experiences for them, and they share the suffering, the loss of control, and the impaired quality of life (Ferrell, Cohen, Rhiner, & Rozek, 1991).

Why Suffering Is Unnecessary

The prevailing reason for uncontrolled pain at the end of life, cited by more than 90 percent of the hospice contacts, is a medication protocol that does not fit the person's type or intensity of pain.



The prevailing reason for suffering at the end of life is a medication protocol that does not fit the person's type or intensity of pain.

The disturbing reality is that we know how to relieve suffering—but too often we do not use what we know. The person in pain today does not have to wait for a better drug to be developed—he just needs someone to prescribe correctly what we already have.

This most often involves use of the wrong medicines or of doses that are not high enough or not frequent enough or both. It is a problem in all care settings. The disturbing reality is that we know how to relieve suffering—but too often we do not use what we know.

Physicians who specialize in palliative care maintain that there are very few cases in which pain and other symptoms cannot be reduced to a level that is satisfactory to the patient.

- Two hospice physicians report that hospice relieves pain in at least 98 percent of cases (Lynn, 1993; Quill, Cassel, & Meier, 1993).

According to Joanne Lynn, MD, Director of the RAND Center to Improve Care of the Dying: *The person in pain today does not have to wait for a better drug to be developed—he just needs someone to prescribe correctly what we already have* (Lynn, 2000).

Hospice providers have story after story to illustrate the dramatic turnarounds that happen when we do use what we already know. These are two examples:

A family contacted hospice, frantic because for six days their mother had been writhing with uncontrolled cancer pain and retching with uncontrolled nausea. She was not able to keep down fluids or food. A hospice nurse visited immediately, assessed the situation, and contacted the patient's physician with recommendations. She suspected that one of the medicines the doctor had prescribed to relieve pain was actually aggravating the symptoms. Within 45 minutes after the nurse carried out her suggestions (helped the patient swallow a methadone tablet crushed in her favorite pureed fruit), the woman was resting for the first time in almost a week. Her family was overcome with gratitude.

One oncologist was treating a cancer patient in the critical care unit as he tried to control the man's severe pain. The doctor was frustrated because the dose of morphine required to relieve the man's distress also made him sleep continuously. He consulted with a hospice nurse, who suggested a switch from short-acting to long-acting morphine. The next day the patient was home—outside mowing the lawn.



With the right medicine, most people at the end of life can have their physical suffering relieved within hours or at most 2 to 3 days.

The vast majority of hospice patients have their pain relieved within 48 hours. They are amazed and grateful. And they commonly ask:

Why didn't anyone do this for me before?

Why doesn't anyone else know what you know?

Why were you able to do this so quickly when no one else could?

With an appropriate medication regimen, most people at the end of life can have their physical suffering relieved within hours or a few days. The vast majority of hospice patients have their pain relieved within 48 hours. People and their caregivers are amazed at how quickly and how well their pain is controlled. Along with expressions of gratitude, hospice contacts reported that they commonly hear questions like these:

*Why didn't anyone do this for me before?
Why doesn't anyone else know what you know?
Why were you able to do this so quickly when no one else could?*

Many of the answers lie in the culture of health care and other barriers to eliminating unnecessary suffering at the end of life.

Obstacles to Improvement

Stakeholders and hospice contacts described several barriers to effective pain and symptom management at the end of life. While much has improved in recent years due in part to surveyor and accreditor scrutiny of pain management standards and practices, many obstacles persist. Those most often noted by stakeholders and hospice contacts include:

- Misery is expected and accepted.
- Doctors don't understand pain management.
- Nursing homes struggle with pain management.
- Access to hospice is limited and late.
- Misconceptions and other factors block relief.

These common and significant obstacles to adequate pain and symptom relief are discussed in more detail below.

Misery Is Expected and Accepted

Health care professionals are socialized in training and practice to maintain emotional distance from patients. The belief has been that such detachment is required to act objectively and decisively in high-stress and fast-paced clinical settings. But along with this detachment comes a tendency to accept patient suffering as an expected aspect of treatment. One physician described the attitude this way:

If we can cure the disease, you should put up with whatever misery the treatment involves and thank us later.

One Surgeon's View of End of Life & Palliative Care

Palliative specialists are experts in the care of dying patients—specifically in improving the quality of their lives...

Dying patients often have pain. Many have nausea. Some have such poor lung function that, although they take in enough oxygen to survive, they live with a constant, terrifying breathlessness—a feeling that they are drowning and just cannot get enough air.

These are patients with untreatable disease, and yet palliative specialists have been remarkably successful at helping them. The key is simply that they take suffering seriously, as a problem in itself.

In medicine, we're used to seeing such symptoms only as clues in a puzzle about where the disease is and what we can do about it...Palliative specialists are trying to change this...The fuss they've raised is forcing physicians to recognize how often we undertreat pain. And they are developing better treatment strategies generally.

Perhaps the most striking observation palliative specialists make, however, is that there is a distinction between symptom and suffering...For some patients simply receiving a measure of understanding...can be enough to control their suffering. A doctor can still help, even when medications have failed.

Atul Gawande, *Complications*, 2002, pp. 142-144.

Likewise, the prevailing attitude in a large teaching hospital was characterized as:

You're in the hospital—you're not SUPPOSED to feel good and you WILL have painful procedures.

Others pointed out that many patients also accept misery. People witness or hear about dying without appropriate pain and symptom management and come to expect the same for themselves:

People don't expect much. They don't realize that they don't have to have pain; they think it goes with the disease.

Physicians may be less likely to tolerate suffering in patients who are dying than in patients they are trying to cure, but often the impending death is not acknowledged until late in the patient's decline. As hospital stakeholders noted:

Many deaths in the hospital happen in a critical care unit, most often after a trial of aggressive treatment. Such treatment involves painful, invasive procedures like intubation, ventilation, suctioning, and insertion of central lines. These interventions cause pain for the patient and emotional distress for the family. It is torture for both.

Doctors Don't Understand Pain Management

Over and over again hospice contacts from all regions in Michigan described shortcomings in physicians' understanding and management of their patients' pain. Many of the problems reflect a lack of familiarity with basic pain relief principles. For instance:

Doctors don't understand pain management. They are uncomfortable going beyond a certain ceiling of analgesic dose. They don't understand that people can walk, talk, and function well on high doses of meds. Too low a dose is the most common reason for unmanaged pain.

Doctors think about pain but they are not knowledgeable. They misdiagnose the type of pain and the patient is under medicated or has no pain meds. Or they don't know to use long-acting as well as short-acting opioids so the patient can get relief without sedation.

Many oncologists start morphine for patients' discomfort but they don't know adjuvant therapy (other medicines that work with morphine for better relief). They don't know how to treat

What a Difference Two Days Make

"After six days on hospice care Mr. B told me: "I was so sick, Susan! My wife was sitting in the hospital with me and I held my finger (like a gun) to my head and told her 'I can't do this any longer!' Then I started with hospice and in TWO DAYS I wanted to live again!!"

Six weeks later Mr. B has enjoyed every day since. He is living in our hospice residence and nearly every day takes drives with his wife, has lunch in a park, visits his cronies in his village, and just plain enjoys the day. He and his family are excited about his care and his quality of life."

atypical pain, like muscle spasms. Many patients with unmanaged pain have metastasized cancer with nerve or bone pain, and the prescribed medicines don't work for the type of pain they have.

It is not surprising that many doctors are not skilled at pain and symptom management for the end of life. Although the science of palliative medicine has been evolving for decades, the strategies for symptom relief were used mainly for hospice patients until recent years when palliative medicine was recognized as a medical specialty. Because few doctors have received training in palliative techniques, the drug combinations are unfamiliar to most and some of the doses range higher than was considered safe in years past.

Physicians who have not kept pace with these advances may be unaware of newer pain protocols or apprehensive about prescribing the drugs and doses. Nurses who share this lack of awareness may be reluctant to administer the medicines and dosages common in hospice and palliative care. According to interview contacts this uncertainty occurs in all health care settings and causes people to suffer unnecessarily at the end of life with pain, shortness of breath, nausea, and other distressing symptoms.

The American Society of Clinical Oncology (1998) surveyed 3,200 oncologists in 1997 to assess their treatment of cancer patients. These are some critical findings:

- 95 percent of oncologists felt competent to manage pain, but 25 percent do not provide optimal pain management. (This was assessed by their answers to vignettes designed to elicit actual practices.)
- 56% report difficulty getting palliative care consultations for terminally ill patients.
- More than half report that more than 20 percent of their patients die in pain.
- Oncologists are more likely to provide chemotherapy beyond the point of usefulness if they:
 - Have strong feelings of failure when a patient becomes terminally ill; or
 - Have anxiety about telling a patient that he or she will die soon.
- A majority of oncologists (64 percent) receive requests for euthanasia or physician-assisted suicide.

Education of physicians and access to palliative care services remain the greatest obstacles to providing quality end of life care.

Nursing Homes Struggle with Pain Management

Nursing homes provide end of life care in the face of daunting challenges. The residents who die there are very elderly—in 2002, 53 percent of decedents in Michigan facilities were 85 and older and 32 percent were 75 to 84 years old. Most have a combination of functional limitations—such as inability to eat, bathe, get out of bed, toilet or walk alone—and more than half have dementia or other cognitive impairment that complicates communication (Krauss & Altman, 1998).

The nursing home industry is heavily regulated to ensure optimum well-being and protection for residents who need rehabilitation. Stakeholders report that there is no good system to ensure management of pain or the expected symptoms of terminal decline.

- Federally mandated assessments include a question about intensity and frequency of pain, but they do not trigger in-depth assessment and focused care planning for pain management.
- Nor is lack of action to relieve pain identified as a violation (an “F-tag”) to be cited by surveyors. States are free to add requirements to be surveyed and tagged for improvement if deficient (in Michigan, M-tags). There is no M-tag for pain management.

The nursing home reimbursement system pays more for rehabilitation and skilled technical procedures than for intensive personal caring and end of life symptom management. In the face of declining payments overall, administrators may be reluctant to transition residents from a skilled to an unskilled level of care (Zerzan, Stearns, & Hanson, 2000). For their part, nursing home residents and their families are reluctant to bypass up to 100 days of Medicare room and board payments in favor of hospice care for which Medicare pays no room and board.

Minimum staffing levels limit chances to anticipate, assess, and support the needs of dying people in nursing homes.

- The average number of nursing contact hours per resident per 24-hour day is 3.9 in the United States and 3.7 for Michigan facilities—36 minutes from a registered nurse, 42 minutes from a licensed practical nurse, and 2 hours and 24 minutes from nursing assistants (Nursing Home Compare, n.d.).



Pain is out of control in nursing homes. A key issue is that nursing home medical directors remain reluctant to order opioids. In some facilities they lack knowledge of pain management 101 and they're unwilling to order appropriate medicines.

Staff ability and commitment to assess discomfort when the resident can't communicate well varies widely. Residents who have pain medicines prescribed to take as needed may not get them unless they ask, even if their ability to ask is compromised—for example, persons with dementia. The literature indicates that persons with dementia receive half as many pain medications as persons without dementia.

- High turnover of employees at all levels (administrators, directors of nursing, nurses, and assistants) results in loss of champions for quality improvement and end of life care. This makes it difficult to keep employees trained in and confident with end of life pain and symptom management.

Nursing homes in Michigan vary in their ability to provide quality care. About half have received onsite mentoring ordered by state surveyors to address deficiencies. These facilities may struggle to provide basic care and lack the resources, stability of staff, and commitment for quality improvement activities.

Likewise, nursing homes vary in expertise and effort devoted to pain management. In 2003, 64 better-performing facilities enrolled in a two-year quality improvement project to advance pain management for residents (MPRO, 2003). At the beginning some facilities had no tools and no process for assessing pain, but after the first year the prevalence of pain dropped by 7 percentage points across the entire group. The weakest aspect of the pain management process for the nursing homes was the lack of ongoing monitoring of both pain and the response to medication.

These representative comments from interview contacts relate to end of life care in nursing homes:

Even when pain is assessed, relief may be delayed. Sometimes a facility is so short staffed that the nurse has all she can do to pass the medications for her shift. There may be no time to call the doctor for an order for a pain medication, or the doctor may not call back. This is frustrating for the nurse. In some facilities the pain problem is noted in a log that the medical director checks when he visits once a week or once a month.

When pain is assessed and a medication is ordered, there may be no follow-up to evaluate whether the drug is given and whether it provides effective relief.

A high percentage of nursing home residents have dementia, and it can be difficult to interpret the meaning of changes in their behavior. When behavior changes, facilities tend to lean toward dementia rather than pain as the reason for the change. Only forward-thinking facilities consider pain as the problem and do a trial of a mild analgesic. According to the literature, most often the pain medicine does help.

Nursing home teams were concerned that pain medication side effects would make people too drugged up and increase their risk for falls.

Nurses do their best within their own realm of comfort, but some are scared of the medicine or the dose or both. So when medicines are ordered as needed for breakthrough pain, the residents may not get them as often as required for good relief. Some nurses don't even think to medicate people before painful procedures. Even when a person is actively dying, some fear that if they give what turns out to be the last dose of pain medicine they may be blamed for the person's death.

Access to Hospice is Limited and Late

In Michigan about one-third of persons who die use hospice services. Table 5.2 compares the actual number of deaths with an estimated count of hospice recipients in selected categories.

		Actual Number of Deaths	Estimated Hospice Recipients	
			Number	Percent
Age	All Ages	87,534	29,400	34%
	0-34 yrs	4,008	353	9%
	35-64 yrs	18,773	5,586	30%
	65-84 yrs	41,111	15,876	39%
	85+ yrs	23,641	7,350	31%
Place of Death	Hospital	39,897	4,998	13%
	Nursing Home	21,219	4,998	24%
	Home	23,541	16,170	69%
Race	White	74,027	25,872	35%
	Black	12,698	2,911	23%
Dx	Cancer	19,831	14,083	71%

Source: 2002 Michigan Resident Death File, Vital Records and Health Data Development Section, Michigan Department of Community Health; Michigan Hospice and Palliative Care Organization, Michigan Summary Report from 2002 National Data Set

It is telling that while almost the same numbers of people die in the nursing home as at home, there are more than three times as many

hospice recipients in the home setting. This reality underscores the limited access to hospice in nursing facilities.

Note that the highest proportions of hospice recipients are found among these groups:

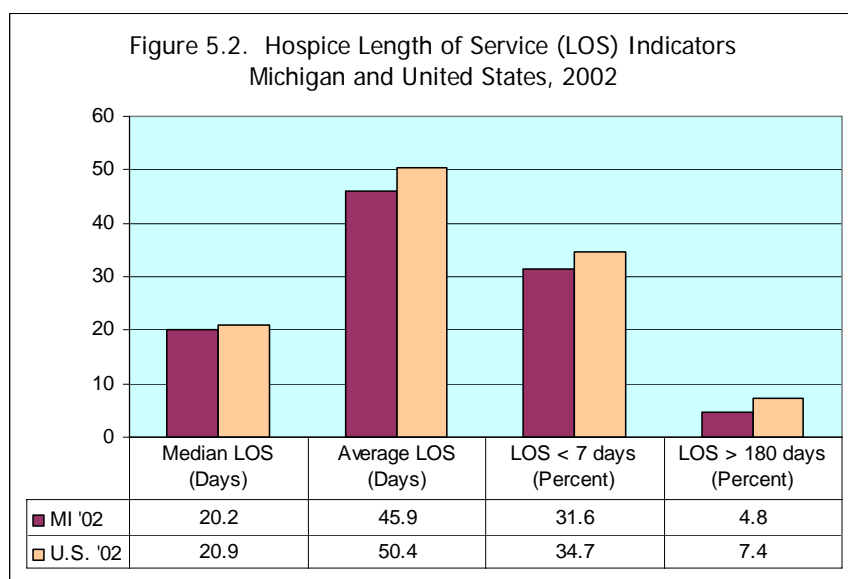
- People who die at home (69 percent); and
- People who have cancer as the cause of death (71 percent).

The least hospice use occurs at younger ages, in hospitals and nursing homes, and among African Americans. It is likely that hospice use will always be lower in the younger age range. They have a high incidence of trauma deaths which are sudden and not hospice-appropriate. And parents are reluctant to stop curative attempts for children with life-limiting illnesses.

Access to hospice care comes late in the course of terminal decline for almost two-thirds of people who receive services.

- A review of all 621,100 hospice discharges in the United States in 2000 found that 63 percent received service for less than 30 days (National Center for Health Statistics, 2003).
- Medicaid recipients and people who lived in a health facility (hospital, nursing home) during their hospice care had shorter lengths of service than others.

Length of stay indicators reported by Michigan hospices for 2002 are displayed in Figure 5.2.



Source: Michigan Hospice and Palliative Care Organization, Michigan State Summary Report - 2002 and 2002 NHPCO National Data Set

Compared to the United States, Michigan providers had lower median and average lengths of service and fewer very short and very long admissions.

- Half of hospice recipients had service for less than 3 weeks and almost one-third for less than 1 week before they died.

With periods of service as brief as 7 days people are unable to experience the full benefit of hospice support, even though families do express high satisfaction with service as brief as 1 day. The high prevalence of hospice patients admitted with severe pain and the high prevalence of short lengths of service add up to weeks and months of unnecessary suffering prior to hospice care. At the other end of the spectrum, fewer than 5 percent had service for more than 6 months.

Of the 57 interviewed hospice contacts, 28 were able to provide 2002 data for median length of service (MLOS) and 21 for admissions shorter than 7 days. Table 5.3 shows the distribution of responding agencies by median length of stay.

- For 86 percent of the hospices one half of patients died within one month.
- For almost 40 percent, one half died within 2 weeks.

While some of the admissions undoubtedly reflect a precipitous decline, it is likely that many of the rest reflect brink of death referrals following weeks of unnecessary suffering. All but one of the agencies reporting median lengths of service longer than 3 weeks are located outside of southeastern Michigan. Six of the agencies with MLOS below 15 days were located in the Thumb and southeastern regions of the state.



Half of hospice recipients had service for less than 3 weeks and almost one-third for less than 1 week before they died.

The high prevalence of hospice patients admitted with severe pain and the high prevalence of short lengths of service add up to weeks and months of unnecessary suffering prior to service.

Table 5.3. Distribution of 28 Hospices by Median Length of Service, Michigan 2002

Median LOS	No. of Hospices	% of Hospices
≤7 days	1	3.6%
8-14 days	10	35.7%
15-21 days	9	32.1%
22-28 days	4	14.3%
29-35 days	2	7.1
36-43 days	1	3.6

50 days	1	3.6
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Table 5.4 shows the spread of the 21 reporting agencies by percent of new patients that died in less than 7 days. For 71 percent of the hospices, one or two patients of every five receive service for fewer than 7 days before death.

Table 5.4. Distribution of 21 Hospices by Percentage of Patients Who Die within 7 Days, Michigan 2002		
% of Patients	No. of Hospices	% of Hospices
>40%	3	14.3%
21-40%	15	71.4%
0-20%	3	14.3%

Such brink of death referrals rob the patient and family of optimum hospice support. They also are expensive for the agency, since the admission process involves a flurry of visits and equipment and medication deliveries. More than one hospice contact described the frustration and even guilt that team members feel because they have not been able to provide full hospice support for the patient and family in such a short time.

Access to Hospice in Nursing Homes

Access to hospice care in nursing homes is limited nationally, despite the fact that two-thirds of permanent (full-year) residents and one-half of part-year residents die there (Hogan et al., 2000). Medicare and Medicaid recipients who live in nursing homes can only receive hospice care there if the facility chooses to contract with a hospice provider. Doing so is optional, and the actual use of the Medicare hospice benefit by nursing home residents is far less than the expected need for such care. Most often hospice is ordered not at all or late in the course of decline.

Petrisek and Mor (1999) examined the distribution of hospice recipients in nursing homes nationally. These are their findings:

- 70 percent of facilities had no hospice recipients.
- 26 percent had fewer than 5 percent of residents on hospice.
- Only 4 percent of facilities had 5 percent or more residents enrolled.

These are the results for Michigan nursing homes:



Not many nursing facilities contract with hospice for their residents. Researchers report that data from Michigan nursing homes show:

- 60 percent ($\pm 5\%$) had no hospice recipients.
- Less than 1 in 20 had 5% or more of their residents on hospice.

Hospice lengths of stay are short in nursing homes. 77% of residents receive service for one month or less.

- 60 percent (± 5 percent) had no hospice recipients.
- Fewer than 5 percent had 5 percent or more of their residents on hospice.

In Michigan nursing homes in 1998, hospice days of care accounted for less than 1 percent of total days of care for the year (Michigan Department of Community Health, 1998). In another large national study of hospice recipients in nursing homes, Miller, Gozalo, & Mor (2000a) found that:

- 25 percent received care for fewer than 7 days before death.
- 52 percent received care for 30 days or less.

Comments from interview contacts mirror the statistical picture. A common lament from hospice contacts across the state was that some nursing homes are far more likely to accept an occasional hospice recipient whose family can no longer provide care at home than to consider which of their current residents could benefit from hospice care. Many facilities are so reluctant to offer hospice services that they contract with hospices on a patient by patient basis rather than committing to blanket agreements for longer time periods. Because nursing homes are themselves providers of end-of-life care, it is not uncommon for hospice nurses to encounter defensive and resentful reactions about why they are there and what value they add.

The Michigan Hospice and Palliative Care Organization reports that 17 percent of an estimated 29,400 hospice recipients—about 5000 people—received services in nursing homes in 2002.

- There were 21,219 registered deaths in nursing homes in 2002.
- That leaves more than 16,000 people who died in long term care facilities in Michigan without the benefit of palliative care through hospice.

A major study of the value of hospice in nursing homes found that hospice/nursing home collaboration makes a difference in residents' pain control and quality of life. Compared to those who did not receive hospice care, residents who did enjoyed these benefits:

- Their daily pain was far more likely to be detected and treated regularly.
- They experienced less shortness of breath



Of the 21,219 nursing home residents who died in 2002, only about 5000 received hospice services.

That leaves 16,000 people who died in nursing facilities without the benefit of palliative care through hospice.

A major study of the value of hospice in nursing homes found these benefits for hospice recipients:

- Pain detected and treated
- Less shortness of breath
- Less likely to be hospitalized
- Fewer invasive procedures
- Less use of physical restraints

- They were less likely to be hospitalized in their final months of life.
- They had fewer invasive procedures (feeding tubes, injections, and intravenous infusions), lower use of physical restraints, and less likelihood of physical, occupational, or speech therapy.

In nursing homes with higher proportions of hospice recipients, there were notable spillover effects as facility nurses applied their hospice learnings to better assess and manage pain and symptoms for non-hospice residents. (Miller, Gozalo, & Mor, 2000b).

Access to hospice in nursing homes may be blocked because the resident is not recognized as nearing the end of life by the MDS assessment nurse. Lacking that designation, the resident may receive restorative care to maximize function and intake rather than palliative care to maximize comfort and closure.

Consumer Barriers and Misconceptions

Although 50 percent of terminally ill patients have moderate to severe pain, only 30 percent of them wanted additional treatment from their physician in one study (Weiss, Emanuel, Fairclough, & Emanuel, 2001). These are explanatory factors:

- About one third of terminally ill patients cited a desire to avoid the side effects of opioid analgesics. They preferred to balance pain and troublesome side effects.
- About one third are reluctant to take pain medicines because they fear addiction. Families may fear this as well.

The American Medical Association Council on Scientific Affairs (1995) adds these factors:

- Patients may be reluctant to report their pain. Some may be stoic. Others may wish to avoid facing the possibility that increased pain means progression of the disease.
- People may hold the common misconception that taking too large a dose early on will prevent the drug from being effective when they really need it.

Older people tend to under report their symptoms. Those with dementia are at particular risk of poor pain control because their communication problems make them less able to report pain. It

also is more difficult for clinicians to assess their pain properly (Davies & Higginson, 2004a).

Encouraging Factors

Balancing the obstacles to improvement are factors that support change. These include model policies, promising programs, and professional resources.

Model Policy

Federation of State Medical Boards (FSMB)

The FSMB is committed to assisting state boards in protecting the public and improving health care. In 1998, the board introduced a Model Policy for the Use of Controlled Substances for the Treatment of Pain (“Model Policy,” 2004). The policy was strengthened and updated in 2004. Michigan boards recently adopted a modified version of the 1998 policy.

Consensus Statement

One of the obstacles to effective pain management is physicians’ fear of scrutiny and possible prosecution for prescribing too many controlled substances. At the state level, there may be friction between public health and law enforcement agencies over the proper balance between drug control policy and pain treatment.

In 2001, the U.S. Drug Enforcement Agency and 21 pain and health organizations issued a consensus statement calling for balance between drug control and pain relief (American Pain Society, 2001).. The document can serve as a template for consensus at the state level.

QI Guidelines

The American Pain Society (1995)has developed guidelines for quality improvement programs to enhance treatment of acute pain and cancer. These are available to health care facilities that have not yet achieved system change to adopt pain as the fifth vital sign. The society also has developed a position statement on Treatment of Pain at the End of Life (“Treatment of Pain,” n.d.). This document is a useful model to guide state efforts to achieve a balanced drug program.

JCAHO Pain Standards

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO, 1999) launched pain management

standards effective January 1, 2001. They apply to all hospitals, home care agencies, nursing homes, behavioral health facilities, outpatient clinics, and health plans that seek JCAHO accreditation. Requirements include processes for assessing treating pain as well as educating staff and establishing pain policies and procedures. The Michigan Commission recommended that all nursing homes be required to meet JCAHO standards.

Promising Programs

North Carolina Medical Board

The North Carolina Medical Board has implemented and reported a successful process for communicating the state's controlled substance guidelines. It is a useful example of a proactive approach to developing and communicating a policy to improve pain management and end of life care (Joranson, Gilson, & Nischik; 2002).

Rhode Island Nursing Home QI Project

Rhode Island has completed a successful quality improvement initiative to improve pain management in nursing homes ("Nursing Homes Register," n.d.). The outcome was a 41 percent reduction in pain among residents. They plan to publish their results and create a website by 2006 with strategies posted. This may be a useful model for Michigan to evaluate.

Rhode Island Palliative Care Consultations

Hospice and nursing home providers have partnered with academic researchers to pilot two promising approaches to improve pain management in nursing homes. One is an effort to build palliative care teams in nursing facilities. The other is a nurse practitioner pain and palliative care consult service for nursing homes (Teno, 2002).

Palliative Care Programs

Several Michigan hospitals have well-established palliative care services that can serve as models for others who are planning to launch programs. There also are nursing homes that have implemented successful quality improvement programs that targeted pain management. They are potential mentors for their peers.

Professional Resources

Long Term Care Advocates

Michigan has a rich supply of geriatric and long term care specialists that have worked steadily to create positive change in nursing homes. They have designed process guidelines for end of life care and pain management in nursing homes. Their work provides a solid base for continued improvement, and their talent is immense.

Palliative Care Clinicians

Michigan has a greater than usual supply of nationally respected palliative care leaders in all disciplines. Their talent is matched by zeal for progress. They are a rich resource for future action.

University of Wisconsin Pain and Policy Studies Group

This group of consulting academics was very helpful to the pain management subgroup of the Michigan Commission on End of Life Care. They labor on the cutting edge of pain policy and have a website with useful resources. They may be a resource to use if needed to assist with balancing drug control and pain policy in Michigan.

Implications for Policy and Programs

There are a number of useful strategies to consider to eliminate unnecessary suffering at the end of life in Michigan.

Use QI Methodology

There is strong evidence that pain is prevalent and too often untreated despite clear, appropriate clinical guidelines. Where there is a gap between the local practice and the standard of care, the solution lies in a quality improvement (QI) approach. Health care providers need to apply treatment and models that have already been proven effective. QI methodology should drive efforts to improve pain management practices in Michigan.

Increase Access to Palliative Care in Hospitals

Palliative care principles and programs work to improve pain management in any setting. There are successful programs in Michigan that can be adopted by more health care providers. It also would be useful to examine innovative models that have succeeded in other states—some of the Rhode Island work, for instance. Recommended initial strategies include:

- Partner with the Michigan Health and Hospital Association to assess status and scope of palliative care services in Michigan hospitals.

- Assess interest in a palliative care network for active programs.
- Explore models for palliative consultation for health care systems that have no local expertise.
- Poll EPEC-trained and board-certified palliative specialists regarding potential roles in training and consulting with peers.

Increase Access to Palliative Care in Nursing Homes

Nursing homes have an unfortunate combination of serving the most challenging population and having the greatest need for and the least expertise in palliative care. Rapid change is needed. Quality improvement projects have been moderately successful in decreasing pain levels, but progress has been slow. Although there are many facilities that are not yet capable of continuous quality improvement, their residents still have a right to adequate pain control. Recommended initial strategies include:

- Assemble long term care partners to solicit input and plan and guide action.
- Target facilities with very high and very low pain levels and assess the reasons for the differences.
- Investigate models for palliative care teams and consults and assess their feasibility for Michigan. Consider funding demonstration projects.
- Consider policy options if necessary:
 - Create an M-tag to make poor pain management an inspection violation.
 - Mandate adherence to the JCAHO pain standards.
 - Require each nursing home to contract with at least one hospice.

Balance State Drug Policy

According to stakeholders, there is reluctance in state government to confront the balance of drug control and pain management in state policy. Medical boards have not enforced mandated continuing education in pain management, and the MDCH has not reinstated a substance abuse advisory committee. Physicians still feel monitored by the Michigan Automated Prescription Service. It is true that education is not the entire answer, but it is an essential part of the solution. Physicians cannot apply what they do not know. Recommended initial strategies:

- Interview key MDCH contacts to assess the current status and politics of the situation. Decide whether further action is required and identify the proper facilitator.

- Solicit support for physician education from the medical societies.

Educate Physicians

Training is necessary but not sufficient for behavior change. Local training may generate better participation. Recommended initial strategies include:

- Poll EPEC-trained and board-certified palliative specialists regarding potential roles in training and consulting with peers.

Educate Consumers

Consumers need education to help them understand that they need not expect and accept misery. One approach is a public awareness media campaign, but that must be supplemented with community outreach to make the message stick. Recommended initial strategies include:

Search the literature and contact the American Association of Cancer Pain Initiatives for information about other successful campaigns.

Contract with an advertiser who will use a social marketing approach.

Consult with palliative care experts to identify message content.

Pretest the content with a focus group.

Key Points

Inadequate pain and symptom management is widespread in Michigan. It is a problem in their service areas for nine of every ten hospices. Almost one half of hospice contacts estimated that 50 percent of their enrollees come to them in severe pain.

Three or four of every ten Michigan decedents suffer severe to excruciating pain for the final few months. This is true in hospitals, in nursing homes, and in home settings.

The prevailing reason for suffering at the end of life is a medication protocol that does not fit the person's type or intensity of pain. Doctors do not use proven methods to relieve suffering.

In Michigan nursing homes, 40 percent of terminally ill residents suffer from severe to excruciating pain. Their pain is not well assessed or treated. Yet 60 percent of the facilities have no hospice patients. 16,000 vulnerable elderly died in Michigan nursing homes in 2002 without palliative care.

Several problems cause suffering to persist. Doctors and patients accept misery as normal. Physicians are not skilled at pain management, and nursing homes struggle with it. Access to hospice is limited and late. Consumers believe myths that make them reluctant to take strong medicine.

One third of hospice recipients receive service for less than one week before they die. One half get hospice for three weeks. Almost all patients who are admitted in severe pain have their discomfort relieved within a day or two. Sometimes it takes just hours. They wonder why no one was able to help them before.

Michigan can take advantage of model policies and programs from other states to relieve suffering here. The state also has a rich supply of talented professionals and innovative programs.

There is strong evidence that pain is prevalent and too often untreated in Michigan despite clear, appropriate clinical guidelines. Strategies to reduce suffering include improving access to palliative care in hospitals and nursing homes; educating physicians and consumers; and working to balance state drug and pain policies. A quality improvement approach will help to bridge the gap between standards and practice.