

*Lansing, Michigan
July 2002*

To Governor Engler:

In accordance with the Executive Orders of June 11, 1999, and January 24, 2000, the Michigan Commission on End of Life Care is pleased to present to you its final report.

This document represents the second of the three work products the Commission was charged to produce: the Commission's recommended model state and institutional policies for end-of-life care, along with the results of the Commission's survey on the availability and cost of public and private insurance coverage for hospice services, pain management, and palliative care. An abridged version of this report was delivered to you on August 30, 2001, and is available on the State of Michigan Web page at: www.mchigan.gov/mdch . Click on Physical Health and Prevention, choose Services for Seniors, then End of Life.

The third work product, an inventory of existing resources available to Michigan citizens for end-of-life care planning, will be published in the form of a resource guide for end-of-life care planning and will be distributed to the public.

On behalf of the Commission, we would like to thank you for the opportunity to serve Michigan by examining this complex subject. We are pleased that our work played a part in passage of fifteen bills in 2001 that you signed. These new laws represent the essence of our focus – to improve the quality of and access to end-of-life care for citizens of our State.

Sincerely,

Rev. Clayton L. Thomason, JD, MDiv
Chair

Michigan Commission on End of Life Care

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I. Executive summary of recommendations.

Many of these recommendations were made in response to barriers to care the Commission identified early in its study of end-of-life care. These are summarized in Appendix VIII(C).

General.

1. The Governor and the Legislature should adopt these principles in formulating public policy for end-of-life care:
 - a) The end of life is an important time in the life cycle of all Michigan citizens. People facing the end of their life should have optimal comfort and support.
 - b) All Michigan citizens should be encouraged to engage in caring conversations with their loved ones concerning their expectations and wishes for end-of-life care, and to plan for their financial, emotional, legal, and spiritual needs at the end of life.
 - c) A model of palliative care should be integrated into treatment modalities, beginning at diagnosis of a life-limiting condition and continuing throughout the course of illness and beyond, regardless of outcome.
 - d) Children living with life-threatening or terminal conditions deserve intensive symptom management, palliative care, and respite programs that meet their special needs.
 - e) People who live with advanced severe illness and die in long-term care settings are a uniquely vulnerable population whose interests at the end of life must be defined, protected, and advanced.
 - f) The lack of effective pain and symptom management is a public health issue that requires the highest level of professional and regulatory attention.

2. The Governor, the Michigan Department of Community Health (MDCH) and the Michigan Department of Consumer and Industry Services (MDCIS) should initiate a statewide awareness and educational campaign for the public and for health care professionals. This campaign should be culturally sensitive and should recognize varying approaches to end-of-life care based on spiritual and cultural beliefs and life experiences. The topics of this campaign should include:
 - a) Awareness of all aspects of medical decision-making, including the importance of designating a patient advocate and fully exploring all options for treatment and care
 - b) Laws concerning the designation of patient advocates, guardians, and other surrogates
 - c) The principles of pain and symptom management

3. MDCH should nurture an ongoing coalition of public and private stakeholders that will reshape health care delivery systems to provide appropriate and competent curative and palliative care services. These services should be designed around the needs of patients and families rather than those of the providers of services, should eliminate barriers to access, and should realign financial incentives as appropriate.
4. MDCH and MDCIS should develop public policy and draft regulations for end-of-life care based on standards developed by experts in the field in order to promote competent and appropriate care for Michigan residents living and dying with advanced illness.

Professional education. *(See also page 39 of this report.)*

1. Health professional schools or educational programs should include in their core curricula content on end-of-life care appropriate to each discipline, including knowledge, skills, and attitudes. They should:
 - a) Charge at least one faculty member with developing this curriculum
 - b) Regularly assess and evaluate both didactic and experiential curriculum content, consider the professional expertise of faculty involved in end-of-life care education, support faculty development and draw on the experience of community professionals
 - c) Work collaboratively with other schools within each discipline and within the larger educational institution to enhance instruction in end-of-life care
 - d) Develop new models of education that incorporate adult learning principles and interactive learning to improve the abilities of physicians and other professionals as they care for people who are dying
2. MDCH should take a leadership role in exploring options for end-of-life care education innovation grants to support curriculum assessment, development, and evaluation by individual schools and educational programs; and for development of interdisciplinary and inter-institutional efforts to improve end-of-life education.
3. MDCH, MDCIS, and all applicable health profession licensing boards should promote and advance the art and science of end-of-life care in education of all health professionals at all levels and should promote palliative care as a defined area of expertise, education, and research, all to the end of attaining the best possible end-of-life care for all Michigan citizens.

Pain and symptom management. *(See also page 46 of this report.)*

1. MDCIS should adopt licensing requirements for health facilities and agencies that promote service- and unit-specific education programs for all health professionals on effective pain and symptom management.

2. In order to effect institutional change, MDCIS and MDCH should adopt by regulation and monitor the progress of licensed health facilities and agencies in implementing the requirements for treatment of pain of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) so that facilities demonstrate effective and acceptable assessment and treatment of pain for each patient in an individual and timely manner.
3. All applicable health profession licensing boards should adopt and disseminate the “Model Guidelines for the Use of Controlled Substances for the Treatment of Pain,” promulgated by the Federation of State Medical Boards, and adopt policy declaring that undertreatment and inappropriate treatment of pain will be scrutinized.
4. The Legislature should add a subsection to the Policy on Patient and Resident Rights and Responsibilities within the Public Health Code, stating that all patients have the right to adequate pain and symptom management and palliative and hospice care.
5. The Legislature should amend the Michigan Dignified Death Act (MDDA) to eliminate the terminology “life expectancy of less than six months” and replace it with language to require physicians who identify a patient with limited life expectancy due to advanced illness to provide the patient with information about options for management of pain and symptoms. Such information should be provided regardless of whether the patient continues on a course of curative medical care or combines this with or chooses palliative care or hospice care. MDCH and MDCIS should take a leadership role in disseminating information about the MDDA to professionals and the public because it is little known among physicians and is largely disregarded by them.
6. The Legislature should amend all statutes to eliminate the use of the term “intractable pain” or amend it to read “pain” as appropriate.
7. The Legislature should repeal the Official Prescription Program (OPP) because in its current form the OPP impairs access to effective pain management without a corresponding benefit in the control of prescription drug diversion or quality of pain management.
8. The Legislature should replace the current OPP with a system that supports electronic monitoring; is balanced in its approach to high-quality pain management and its desire to limit prescription drug diversion; requires no additional special prescription form; is efficient and invisible to the patient and practitioner; and provides information that is well understood and available to all those who need it.
9. The Legislature, MDCH, and MDCIS should work to minimize state regulatory impediments to effective pain medications and should work with the Michigan Congressional delegation and federal officials to minimize federal regulatory impediments concerning prescriptions, including the time limits for filling them, prohibitions on refills, telephone orders, and electronic transfer of prescriptions.
10. MDCIS should develop a system and promulgate rules that require pharmacies to help patients find adequate supplies of pain medications when the pharmacy is unable to fill a valid prescription as presented.

11. MDCH and the MDCIS Office of Financial and Insurance Services should encourage health plans and payors to minimize copays, deductibles and other restrictions on reimbursement for opioids prescribed for pain and symptom management.

12. MDCH, MDCIS and the Department of Environmental Quality should explore ways to improve disposition of pharmaceuticals when no longer required for home use, such as by requiring that in settings that have a central point of control such as a nursing facility, hospital, or hospice program, unused pharmaceuticals be retrieved and redistributed to other patients with legitimate prescriptions. This will limit waste of medical resources and reduce costs. The Department of Environmental Quality should advise on the effects of pharmaceutical waste on the environment and methods to minimize any detrimental effect.

Reimbursement. *(See also page 78 of this report.)*

1. MDCH should assess and validate existing Michigan data to determine how to optimize care at the end of life by analyzing, redistributing, and redesigning incentives in order to provide more options concerning types and settings of care.
2. The Governor, MDCH and MDCIS should work with the Michigan Congressional delegation and federal agencies to further understand and explore current or proposed federal laws and regulations for Medicare and Medicaid, to determine the impact, particularly in Michigan, and make changes where appropriate, in the following areas:
 - a) Development of an outlier formula for hospice programs that serve a large number of patients who need higher-cost services or require such services in settings where significant transportation costs exist
 - b) Development of an acuity-based reimbursement formula for the first and last days in hospice in light of the rapidly declining length of stay, which creates an increasing proportion of high-cost days
 - c) Amending the 20 percent limit on inpatient hospice days in relation to total hospice days for programs that can document service to a disproportionately large number of high-acuity patients
 - d) Modifying the Medicare hospice benefit by creating a financially neutral reimbursement methodology for nursing home hospice care so that Medicare beneficiaries can choose hospice care without penalty to the nursing home or eligible residents
 - e) Reimbursing palliative care providers as appropriate to meet patients' and families' end-of-life needs.
3. MDCH should review the final report of the Hospice Residence Research Project to determine if funding the room-and-board component of inpatient hospice residences is a cost-neutral means of delivering patient care.

4. The Legislature should encourage and consider funding research projects designed to evaluate the hypothesis that offering both curative and palliative services concurrently is cost-effective.
5. Health plans and payors should be encouraged to pay the reasonable cost of pain and symptom management, palliative care consultations, and non-pharmacological treatment of pain and symptoms by all types of providers, including physicians, nurse practitioners and members of other disciplines.

Long-term care. *(See also page 92 of this report.)*

1. MDCIS and the Michigan Long Term Care Work Group (LTCWG), together with providers of long-term care, should continue their work to address barriers that interfere with the delivery of quality end-of-life care, including:
 - a) Confusion and conflict concerning the interpretation and enforcement of regulations dealing with avoidable and unavoidable decline and the reluctance to use medications that are perceived to interfere with function such as psychotropic or opiate medications for terminally ill patients
 - b) Lack of adequate pain and symptom management
 - c) A focus on restorative and rehabilitative care as opposed to palliative care or comfort care
 - d) Disincentives for long-term care facilities to offer hospice and palliative services to their residents
 - e) Absence of best-practice models for palliative end-of-life care within long-term care settings
2. The MDCIS and the LTCWG should develop educational and training opportunities in end-of-life care for state surveyors of long-term care facilities, particularly on issues concerning avoidable and unavoidable decline related to the naturalness of dying.

Decision-making for the end of life. *(See also page 100 of this report.)*

1. The Michigan Dignified Death Act should be amended to provide that regardless of whether a patient is terminally ill, physicians should engage in discussions about advance directives during initial consultations, periodic examinations, in-hospital consultations upon admission to or transfer from one health care setting to another, and at diagnosis of a chronic illness.
 - a) Studies should be conducted to determine the best practices for involving physicians in effective discussions with patients about advance directives and actual implementation of advance directives.

- b) Managed care organizations, health plans, and other payors should be encouraged to include medical-record documentation of physicians' discussions with patients as a quality indicator for physician practice.
2. Michigan driver licenses and other identification cards should clearly denote when a person has executed a do-not-resuscitate order and whether a person has an advance directive (and where it can be found).
 3. The State Court Administrator's Office should take a leadership role in seeing that courts, court personnel, guardians *ad litem*, and others are well prepared to administer, enforce, and provide education about the guardianship reform laws passed in 2000.
 4. The MDCH director should establish a working group of advocates, interested parties, and health care professionals to work toward assessing the numerous issues associated with end-of-life decision-making for persons in Michigan who have never been competent and who are terminally ill.

Family issues. *(See also page 113 of this report.)*

1. To promote the health and well-being of all Michigan citizens, the Governor and MDCH should encourage provision of competent respite care to reduce caregiver burden and should encourage health plans and other payors to provide adequate reimbursement for such service.

II. Background of the Commission.

Michigan Governor John Engler established the Michigan Commission on End of Life Care by Executive Order No. 1999-4, issued on June 11, 1999. The Commission's timetable was extended in January 2000 (Executive Order 2000-2) to allow it to achieve synergy with work being performed under a grant from the Robert Wood Johnson Foundation to research and advance end-of-life care in Michigan. (*See Appendix A for complete text of both Executive Orders.*)

Commission membership.

The members of the Commission and their affiliations are:

Dorothy Deremo, MSN, MHSA, RN. Ms. Deremo is president and chief executive officer, Hospice of Michigan, Southfield.

J. Kay Felt, JD. Ms. Felt practices law with Dykema Gossett PLLC in Detroit and is a member of its Health Care Practice Group. She has been active in health care law locally and nationally for more than 30 years.

Thomas M. George, MD. Dr. George is board-certified in the specialties of anesthesiology and hospice and palliative care. He has been medical director of Hospice of Greater Kalamazoo and serves as a faculty member of the Michigan State University Kalamazoo Center for Medical Studies. During the course of the Commission's work, he was elected to the Michigan House of Representatives.

Mary Anne Gorman, MSW. Ms. Gorman is executive director of Hospice of Muskegon-Oceana.

James K. Haveman, Jr., MSW. Mr. Haveman is director of the Michigan Department of Community Health.

Kim K. Kuebler, MN, RN, ANP-CS. Ms. Kuebler is a palliative care nurse practitioner and the owner of Adjuvant Therapies, Inc., in Clare County.

Guadalupe Lara, MSW. Ms. Lara is manager of Supporting Children & Families at Children's Hospital of Michigan, Detroit, and co-founder of the Michigan Hispanic Mental Health Association.

Jeanne G. Lewandowski, MD. Dr. Lewandowski is medical director of pediatrics at Bon Secours Cottage Health Services, Grosse Pointe, and a board member of the American Academy of Hospice and Palliative Medicine.

Sister Mary Giovanni Monge, MA. Sr. Monge is the chief executive officer of Angela Health Care and the founder of Angela Hospice Home Care in Livonia.

Karen Ogle, MD. Dr. Ogle is director of the Palliative Care Education and Research Program in the Cancer Center at Michigan State University and professor of family practice at the MSU College of Human Medicine.

Clayton L. Thomason, JD, MDiv, Chair Rev. Thomason is assistant professor of spirituality and ethics in medicine in the Department of Family Practice and the Center for Ethics and Humanities in the Life Sciences, MSU College of Human Medicine.

Kathleen M. Wilbur. Ms. Wilbur is director of the Michigan Department of Consumer and Industry Services.

Charges to the Commission.

Governor Engler charged the Commission with:

- Identifying, compiling and considering recommendations for improving end-of-life care from public and private organizations throughout Michigan.
- Recommending model state and institutional policies with respect to end-of-life care, including examining and compiling the best ideas of multiple groups currently engaged in examining end-of-life issues and considering these in the development of the Commission's final report.
- Coordinating its efforts with other groups actively engaged in addressing end-of-life issues, including but not limited to the Circle of Life Committee in the Department of Community Health and the Advisory Committee on Pain and Symptom Management in the Michigan Department of Consumer and Industry Services.
- Identifying and evaluating any existing barriers that result in inadequate end-of-life care in Michigan and, where appropriate, making recommendations for elimination or mitigation of such barriers.
- Evaluating the adequacy of education associated with end-of-life care being provided in Michigan schools of medicine, Michigan schools of nursing, and other health professional education programs and, where appropriate, making recommendations to improve such education.
- Evaluating the adequacy of the level and degree of graduate medical education being provided in Michigan residency programs associated with end-of-life care and, where appropriate, making recommendations for changes to improve such graduate medical education.
- Surveying availability and cost of public and private insurance coverage for hospice, pain and symptom management, and palliative care.
- Recommending, where appropriate, state policies concerning end-of-life care related to continuing medical education for health professionals licensed in Michigan.
- Inventorying existing resources available to citizens for end-of-life planning and producing a guide to these resources for the general public.

Guiding principles.

The Commission adopted certain guiding principles for planning, making recommendations, implementation, and monitoring its work.

Its first goal was to gain information about, affirm, and be responsive to core issues related to the end-of-life that reflect the interests and needs of the state's diverse population, including underserved citizens in both rural and urban areas, various racial, ethnic and cultural groups, and all families, even as the definition of family expands.

The Commission also affirmed that end-of-life care is an integral part of a holistic approach to health care delivery and agreed that its work must account for:

- The complementary points of view, interests, and needs of various health care disciplines and the need for interdisciplinary approaches to end-of-life care
- The interrelationship of acute care and palliative care and the need for a continuum of care

- The interrelationship of chronic-illness care and end-of-life care and the need for a continuum of care
- The importance of standardization in education and competency requirements of health care providers in end-of-life care
- The unique, age-related needs of children and adults along the age continuum for palliative and end-of-life care
- The recognition that the “family” are recipients of end-of-life services who are as important as the “patient”
- The importance of after-care and bereavement services for the family and friends of the deceased.

Major committees.

The Commission formed several work groups and three major committees to conduct in-depth investigations in each of three areas: professional education, reimbursement, and pain and symptom management. The latter also covered the Michigan Official Prescription Program (OPP) and its pertinence to end-of-life care. The Commission charged the three committees as follows:

- Committee on Professional Education — evaluate the adequacy of education associated with end-of-life care being provided in Michigan’s schools of medicine and nursing and in professional curricula in other areas of health care; recommend ways to improve this education.
- Committee on Reimbursement — determine the availability and cost of public and private insurance coverage for hospice care, pain and symptom management, and palliative care.
- Committee on Pain and Symptom Management — assess the barriers that exist to adequate and appropriate use of prescription drugs for pain and symptom management.

The research, discussion, findings, and recommendations of these committees are detailed in Chapter V of this report.

Procedures.

The Commission engaged in a number of activities to increase its members’ understanding of the full scope and complexity of the issues having to do with end-of-life care in Michigan. The Commission requested and received reports from a broad range of agencies and citizens with an interest in end-of-life care through several group presentations and five public hearings held throughout the state. (*A summary of the public hearings is found in Appendix B of this report.*)

The Commission gathered data on education, insurance, and the OPP through five surveys, with the actual survey instruments presented in Appendix D:

- Insurance. An Insurance Project Work Group was formed to investigate and analyze specific coverage issues related to end-of-life care in Michigan. The work group developed and conducted a statewide survey of insurers, including all commercial insurers and not-for-profit health care corporations, and produced a report that summarizes their methodology and findings. The work group focused on determining the availability and cost of public and private insurance coverage for hospice, pain and symptom management, and palliative care.

The Professional Education Work Group sought to evaluate the adequacy of Michigan health professional education, residency instruction and continuing education programs, and to recommend improvements. (*See the complete Professional Education Work Group report*).

- Undergraduate health care education. The Robert Wood Johnson Partnership provided survey data on undergraduate core curriculum and end-of-life care education.
- Graduate medical education. The Commission surveyed directors of medical residency programs in Michigan to determine the level and degree of medical education associated with end-of-life care.
- Continuing medical education. The Commission examined continuing medical education opportunities available to Michigan health care professionals and evaluated their value and relevance to end-of-life care.
- The Michigan Official Prescription Program (OPP). The Committee on Pain and Symptom Management designed, field-tested, conducted and analyzed a survey of members of the Michigan State Medical Society and the Michigan Osteopathic Association. They were asked to evaluate the OPP and assess its impact on access to effective pain and symptom management.

End-of-life education and outreach.

The Commission determined its report should be available on the MDCH and MDCIS web pages. The Commission believes these departments need to take the initiative to encourage local community coalitions that deal with end-of-life care and develop a community tool kit to encourage formation of such coalitions.

The Commission also urges the departments to implement a coordinated public information campaign throughout Michigan that encourages caring conversations. This focus would help families share meaningful and loving experiences while making practical preparations for their own health care decisions. The campaign would include these themes:

- Who will make your health care decisions when you cannot make them.
- What kind of medical treatment you want or do not want.
- How comfortable you want to be.
- How you want people to treat you.
- What you want your loved ones to know.

The Commission will also publish a consumer resource guide for end-of-life care planning and resources, which will be widely distributed.

Acknowledgements.

The Commission is grateful for the support provided by the Policy Subcommittee of the Michigan Advisory Committee on Pain and Symptom Management, the Robert Wood Johnson Foundation Michigan Partnership for the Advancement of End of Life Care, the Michigan State Police, the Michigan State Medical Society, the Michigan Osteopathic Association, the Pain and Policy Study Group of the University of Wisconsin, the U.S. Drug Enforcement Administration, individuals within the Office of the Governor, Michigan State University, and the State of

Kentucky; for background information and staff support received from the Michigan Department of Community Health and the Michigan Department of Consumer and Industry Services; and to numerous other individuals who generously offered their time and expertise.

III. National overview.

The care of people living with advanced illness in the United States is undergoing dramatic change due to an unprecedented increase in the number of older adults in the population, the challenges to the health care industry to cope with soaring costs, and the need for innovative models to address the quality of care at the end of life. The emerging field of end-of-life care must respond by developing new practice initiatives and models to help meet the care needs of patients and families living with advanced illness.

Background.

Traditional curative care seeks to arrest the disease process and cure the patient. Acknowledging that this is not always possible, Dame Cicely Saunders organized the first formal hospice setting at St. Christopher's Hospice in London in the late 1960s. Hospice care focuses on enhancing the dying person's quality of life rather than trying to cure the terminal illness. A few years later, in 1975, Balfour Mount, MD, defined the term palliative care and opened the first hospital-based palliative care service, at the Royal Victoria Hospital at McGill University in Montreal. Palliative care focuses on relieving or reducing symptoms of a disease no matter what stage the disease is at, and does not seek to cure the disease. Keeping patients comfortable by treating their symptoms and by using analgesics to relieve pain are important aspects of palliative care. Currently there is an effort to incorporate these principles of hospice and palliative care into regimens for patients in the course of their curative or restorative care, so that they will be utilized more readily by health care professionals and patients before focus is shifted away from curative care.

In the 1990s a pivotal study was undertaken and completed in the United States, called the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). Prompted by concerns over the type and quality of care Americans were receiving at the end of life, the Robert Wood Johnson Foundation funded this project that was conducted at five U.S. teaching hospitals. The hypothesis was that improved communication among physicians, patients, and families would lead to more thoughtful decision making for end-of-life patients, less pain and trauma for the patients, and decreased use of hospital resources such as the intensive care unit (ICU).

Phase I of the study was observational, based on medical record reviews and interviews with patients, patient surrogates, and physicians. The findings were remarkable because, for example, 31 percent of Phase I patients interviewed preferred that cardiopulmonary resuscitation be withheld, but only four percent of their physicians accurately reported this preference during their first SUPPORT interview. In addition, half of all conscious Phase I patients who died in the hospital experienced moderate or severe pain at least half the time during their last eight days of life.

After reviewing the findings from Phase I, physicians at the five hospitals expressed interest in taking part in the second, interventional phase of the SUPPORT study. The physicians and the study investigators decided to try to improve decision making "by providing timely and reliable prognostic information, by eliciting and documenting patient and family preferences and

understanding of disease prognosis and treatment, and by providing a skilled nurse to help carry out the needed discussions, convene the meetings, and bring to bear the relevant information.”¹

Again, the results were distressing. The intervention had virtually no effect on any of the five measures: timeliness of do-not-resuscitate orders, physician-patient or physician-surrogate agreement on withholding resuscitation, days spent in an ICU, frequency and severity of pain, and hospital resource use. The researchers commented that “the study certainly casts a pall over any claim that, if the health care system is given additional resources for collaborative decision-making in the form of skilled professional time, improvements will occur” in these five measures. They also noted, however, that SUPPORT demonstrated that complex end-of-life issues can be studied with scientific rigor.¹

The *Dartmouth Atlas of Health Care* approaches the subject from a different perspective. The *Dartmouth Atlas* series has published compilations of health data for the United States as a whole and for several regions and states, including Michigan. Among the conclusions drawn by its publisher, the Center for the Evaluative Clinical Sciences at Dartmouth Medical School, is that, “Americans at the ends of their lives are not receiving the care that they have said that they want. The dispiriting truth is that, all too often, the supply of resources and the practice patterns of physicians seem to play a more important role than patient preferences in determining the amount and kind of care received at the end of life.”²

Elsewhere, Medicare and Medicaid pay for many end-of-life services, but these public programs have served less as an answer to the many difficult questions in this area than as a starting point for more productive discussion. One such discussion concerns the appropriate relationship among curative, palliative, and hospice care.

About half the states have established commissions or task forces to examine end-of-life issues; most have considered better pain management by physicians, better use of advance directives, and how to overcome financial and other barriers to improving end-of-life care services. At the federal level, Department of Veterans Affairs has disseminated best practices in the care of the dying and has made significant, measurable progress in caring well for dying patients. Still, end-of-life care nationally remains largely a patchwork, and a huge amount of work remains to be done before there is uniformity of policy and practice in end-of-life care across the country.

The following is a brief overview of what has been accomplished, and what remains to be accomplished, in end-of-life care nationwide, drawn largely from *State Initiatives in End-of-Life Care: Policy Guide for State Legislators*, a report issued in 1998 by the National Conference of State Legislatures and the Center to Improve Care of the Dying, Washington, D.C.³

Education and legislation.

Most medical schools offer little — if any — instruction on the important issues faced by dying patients, and a 1997 survey by the American Board of Internal Medicine found that physicians considered themselves ill prepared to deal with end-of-life care issues. Activities and hearings in a number of states and nationally have also made it clear that “the American people remain woefully uninformed about such an important aspect of their lives.” Similarly, a Robert Wood Johnson-funded study of U.S. nursing education programs concluded that “nurses cannot practice what they do not know.”

In 1998, the Institute of Medicine issued a report (“Approaching Death”) that cited the need to:

- Create and facilitate patient and family expectations for reliable, skillful, and supportive end-of-life care.
- Seek a commitment from health care professionals to improve care for dying patients and to use existing knowledge effectively to prevent and relieve pain and other symptoms.
- Address deficiencies in the health care system by measuring quality of care, making providers accountable, adjusting financing systems to encourage better coordination of care, and reforming drug-prescribing laws.
- Improve practitioners’ education in end-of-life issues.
- Make palliative care a defined area of expertise, education, and research.
- Pursue public discussion about the modern experience of dying, including options available to patients and families and community obligations to those nearing death.

State legislatures — or individual legislators — have begun to recognize that there are important issues to be addressed with respect to end-of-life care and that now is the time to address them. Legislation and referenda in California, Florida, Michigan, Oregon, Texas, and other states were attempts to make it easier for Americans to die well.

Understanding pain and suffering.

Recent years have seen greater understanding of pain and suffering and increased determination and ability to respond to patients’ and families’ needs in this area. Some key realizations include:

- People experience suffering throughout the course of illness, not only when close to death.
- Treatment of pain should vary according to a patient’s symptoms, needs, and wishes.
- Treatment of pain and other distressing symptoms improves length and quality of life.
- Even if patients are beyond cure, dying need not involve suffering.
- Barriers to the management of pain and suffering still exist and include practice, regulatory, and societal challenges.

Some states are applying the emerging research-based information through changes in statutes and regulations, development of medical licensing board guidelines, and workshops for medical boards and health care providers. More than a third of the states now have statutes that specifically allow physicians to prescribe controlled substances to relieve pain. Still, regulations and guidelines vary widely from state to state, and a number of public and private national organizations have sought to establish a framework for achieving more consistent policy. The American Society of Law, Medicine, and Ethics Project on Legal Constraints on Access to Effective Pain Relief suggested definitions and provisions that would help enhance pain management through legislation. The U.S. Drug Enforcement Administration clarified its rules on the use of opioids to relieve pain. The Federation of State Medical Boards developed model guidelines for state boards to consider to encourage raising the practice standards of pain management for all patients, including those who are at the end of life, even in times of changing pain management science (*see www.fsmb.org/, “Policy Documents”*).

Financing: “An uncoordinated mix.”

A large proportion of all payment for end-of-life health and other services now comes from the public programs Medicare and Medicaid, but only a small proportion (currently fewer than 20 percent) of Medicare patients enroll in the Medicare hospice benefit, and then only for the last month or so of life. Little is known about how end-of-life care for people less than 65 years old is financed. Services are often fragmented. Aside from hospice care, few medical services target care for patients at the end of life. Instead, services most frequently associated with curative care, such as prescription drugs, inpatient care, durable medical equipment, and home health care are ordered for dying patients. Many services are not covered by health insurance, and data indicate that the out-of-pocket expenses of caring for dying individuals often deplete all savings and other resources (intended for other uses) within households.

In the words of the 1998 *Policy Guide for State Legislators*: “When palliative care and end-of-life services are available, they appear to be covered by an uncoordinated mix of Medicare, Medicaid, private insurance, and private out-of-pocket funds... When private insurers provide coverage, the financing schemes are as numerous as the carriers. There is also great variation in the way services are provided and funded within various settings.”

Many believe that related barriers to good end-of-life care are unique to hospice care and include arbitrary eligibility criteria (principally the rule that says a patient must have a life expectancy of six months or less), and a Medicare requirement for reimbursement that 80 percent of hospice services be provided in the home. Additional barriers include the fact that hospice reimbursement is generally not based on the actual costs of delivering care, and finally, it has been found that cultural attitudes delay the decision to move from curative therapies to end-of-life care options. (All these are discussed in detail later in this report.)

Several demonstration projects in the late 1990s sought to respond to these concerns. The Veterans Palliative Care Initiative, organized by the Department of Veterans Affairs (VA), disseminated best practices in the care of the dying and designed education for VA health professionals to provide caregivers with the skills and attitudes to care well for dying patients. The proportion of VA patients with adequate plans for care at the end of life increased as physicians and patients discussed important issues such as pain management, advance directives, and preferences concerning resuscitation. OPTIONS, a program of the HealthCare Partners Medical Group of Southern California, established a case management program for the coordination of outpatient, skilled, home, and long-term care service. Most OPTIONS patients would not be eligible for hospice care but do have illnesses that are likely to cause death within two years. At the Center to Improve Care of the Dying, at George Washington University in Washington, D.C., MediCaring makes hospice-like services available to Medicare patients with eventually fatal conditions who do not qualify under the hospice six-month rule. That program includes some hospital services that are not always available in hospice.

Advance directives.

All states recognize some form of end-of-life and surrogate decision-making. Although all have durable-power-of-attorney statutes, provisions and language vary widely, they are difficult for the lay person to interpret, and they require patience, effort, and persistence to prepare the

appropriate forms. The fact remains that only one in five adults has completed the equivalent of an advance care plan at the time of death. Unfortunately, even these are frequently too general to provide meaningful direction and often are not applicable to the clinical circumstances of the person's dying. Those advance directives that are applicable often go unnoticed by health care providers.

Community groups, health advocacy groups, and even the National Association of Attorneys General are exploring ways to encourage Americans to share their preferences for treatment at the end of life with their loved ones and to develop standard policies and adequate yet simple forms to communicate these choices to health care providers.

Rejecting assisted suicide.

The U.S. Supreme Court ruled in 1990 that individuals with decision-making capacity have a right to forgo life-sustaining treatment and be allowed to die from underlying disease processes. Then, in 1997, the high court rejected the notion that physician-assisted suicide, the act of physician and patient working together to end the patient's life, was a fundamental right under the U.S. Constitution. They sent the issue back to state legislatures. Only one state, Oregon, has legalized physician-assisted suicide. In November 1998, Michigan voters rejected a ballot measure to legalize physician-assisted suicide.

In concurring opinions in its 1997 decision, U.S. Supreme Court justices implied a willingness to consider that individuals might have a Constitutional right to palliative care in the last phase of life.

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IV. End-of-life care in Michigan.

A. Demographics: An aging population.

Death occurs in all age groups, but it occurs most frequently among older people. Nationally, 70 percent of the deaths each year occur among people age 65 and older. Of the 84,906 people who died in Michigan in 1998, 63,577 (75 percent) were age 65 or older. Of this group, 28,814 (45 percent) were men and 34,763 (55 percent) were women. One-third of all Michigan deaths (27,220) were women age 75 and older. Overall, of those who died, 85 percent were white, 14 percent were black, and fewer than one percent each were Asian/Pacific Islander, American Indian, and members of other races (Michigan Resident Death Files, 1990-98).

There are 1.8 million people age 65 and older in Michigan, but this number is expected to grow significantly with the aging of the baby boomer generation. Most baby boomers are now in their fifties and healthier than previous generations, and they can expect a long life.

Michigan trends will very probably parallel Census Bureau projections that show an increase in the total U.S. population as well as in the median and mean ages of the population over the next 30 years. The economic and health care implications of this demographic shift are clear.

Table IV.1. U.S. Census projections of total population, 2000 to 2030

	2000	2010	2020	2030
Population (in millions)	275.3	299.9	324.9	351.0
Median age	35.8	37.4	38.1	38.9
Mean age	36.5	37.9	39.2	40.2

(Source: U.S. Census Bureau, Population Projections Program, Population Division. January 13, 2000).

There will also be significant shifts within age groups. The traditional caregiver group (ages 20-54) will shrink as a proportion of the total population, while three cohorts – those 55 years old and older, 65 and older, and 85 and older – will continue to swell. To frame this in another way, today all individuals 55 years old and older comprise 35.6 percent of the U.S. population; in 2030, they will comprise 53.1 percent.

Table IV.2. U.S. Census projections of population by age cohorts, 2000 to 2030

Age	2000		2010		2020		2030	
	millions	% of pop.	millions	% of pop.	millions	% of pop.	millions	% of pop.
20-54 yrs	138.1	50.2%	143.5	47.8%	143.3	44.1%	150.8	43.0%
> 54 yrs	58.8	21.4%	75.1	25.0%	95.8	29.5%	107.6	30.6%
> 64 yrs	34.8	12.6%	39.7	13.2%	53.7	16.5%	70.3	20.0%
> 84 yrs	4.3	1.6%	5.7	15.0%	6.8	2.1%	8.9	2.5%

(Source: U.S. Census Bureau, Population Projections Program, Population Division. January 13, 2000).

By 2050, the 85-and-older cohort will be 19.4 million people in the United States and 4.8 percent of the total population, representing a 300 percent increase in the size of that population in 50 years. To use another perspective: life expectancy was 18 years for 99,000 years of human history — until the last century. In 1900, life expectancy increased dramatically to 46 years

thanks to improved sanitation and health care practices. By 2050, life expectancy will be 90 years for many reasons, including better nutrition and advancements in health care. Unfortunately, the population in the future may or may not be healthier even though people are living longer.

Southeastern Michigan trends. The national demographic shift is accentuated in Southeastern Michigan, where, as soon as 2020, people 75 and older will comprise a significant age group in the population.

Table IV.3. Southeastern Michigan population projections by age group

Ages	1990	2000	2010	2020	2030	% change
25-29	393,650	338,376	330,821	338,556	325,824	-17.2
30-34	414,237	339,025	298,838	332,510	325,430	-21.4
35-39	376,299	400,468	328,615	323,271	336,026	-10.7
65-69	183,970	163,490	215,284	321,760	339,293	84.4
70-74	139,092	152,371	149,650	238,467	307,485	121.1
75-plus	210,231	267,639	296,730	351,237	527,961	151.3

Source: Southeast Michigan Council of Governments, in Detroit Free Press, "Era of Elders," Oct. 5, 2000

Nationally and in Michigan, the numbers of people in the age groups usually tapped to be both family and professional caregivers are decreasing at the same time that the elderly population is expanding.

Most frequent causes of death. As the population ages, it is important to note another factor that contributes to the increase in late-life death: the change in the causes of death. In 1900, contagious diseases such as tuberculosis and diphtheria were the leading causes of death. The most recent data from the Institute of Medicine (Field, 1997) and the 1990-98 Michigan Resident Death Files indicate that in Michigan in 1998, the leading causes of death were: diseases of the heart (27,851); cancer (19,442); stroke (5,760); chronic obstructive pulmonary disease (COPD) and allied conditions (3,804); unintentional injuries (3,096); pneumonia and influenza (3,090) and diabetes mellitus (2,449). The number of deaths due to Alzheimer's disease in 1998 in Michigan was 664. These leading causes of death in Michigan echo those across the country, and the top five disproportionately affect older people. Medical treatments make it possible to live with these diseases, but the care is often intensive, prolonged, and often costly. It is also difficult to determine when patients with most of these diagnoses are terminally ill.

These additional Michigan data show the relationship between chronic disease and the increasing ages of people who die.

Table IV.4. Relationship between causes of death in Michigan and being age 65, 1998

	Heart disease	Cancer	Stroke	COPD* and allied diseases	Pneumonia and flu
Total	27,851	19,442	5,760	3,804	3,096
People 65 and older	23,209 (83%)	13,703 (70%)	5,062 (88%)	3,271 (86%)	2,756 (89%)

* Chronic obstructive pulmonary disease. **Source:** Michigan Resident Death Files, 1990-1998.

Where death occurs. It is important to know where people die in order to quantify, qualify, and analyze where end-of-life services are being delivered; doing so assists policy-makers in their work. It also allows those analysts to target and focus their efforts to improve end-of-life care on appropriate populations. In general, people in Michigan and in the nation die in one of three locations. In 1998, 40,466 Michigan residents died in a hospital (47 percent of all those who died), while 19,695 (23 percent) died in nursing homes, and 21,816 (26 percent) were at home. The remaining deaths (fewer than 5 percent) occurred in an ambulance, other institutions or places, or in unknown locations. Compared to national figures, a smaller proportion of Michigan deaths occur in hospitals and larger proportions in nursing homes and at home, but the percentages are nevertheless similar.

Trends from 1990 to 1998 show that the location of death in Michigan has changed — there are fewer deaths in hospitals and more at home and in nursing homes. Nevertheless, at least 70 percent of the Michigan citizens who died in 1990, 1996, and 1998 were in an institution.

Table IV.5. Where people died in Michigan, 1990, 1996, 1998

	Hospitals	Nursing homes	Home	Other
1990 (78,501 deaths)	59%	15.5%	20%	6%
1996 (83,496 deaths)	48.5%	21.8%	25.9%	3.8%
1998 (84,906 deaths)	47%	23%	26%	4%

Source: Michigan Resident Death Files, 1990-1998.

Many advocates consider it a positive trend that an increasing number of people die at home. The increase could reflect an acceptance of the preference to die at home; however, improvements in technology, increased outpatient services, and more access to home health care are all likely contributors to the trend. The other challenge presenting for this increase in people dying at home are the additional burdens to the informal caregivers and the household for services previously rendered by health care providers.

The data also show a decreasing reliance on hospitals for end-of-life care. This may indicate a deterioration of service if it reflects attempts to limit costly inpatient hospital lengths of stay. In spite of nursing homes often being the setting of last resort for most people who are frail, elderly, and disabled, with complex diagnoses and health care needs, these data indicate the nursing facility residents must be included in any targeted end-of-life care quality improvement efforts.

B. Settings in which end-of-life services are delivered.

Following is a more detailed overview of the settings in which end-of-life services are delivered in Michigan.

Acute care.

As the world's thinking about end-of-life care has evolved, many end-of-life services have moved out of the acute-care (hospital) setting into separate hospice programs, other facilities, and patients' homes. However, the need for comprehensive end-of-life services in the acute-care setting is as real as ever, and many hospitals have responded with comprehensive, high-quality programs that address issues ranging far beyond traditional acute care.

The Oakwood Healthcare System in Southeastern Michigan, for example, has developed a Family Matters Support Service that seeks to identify patients and families who have unresolved patient care dilemmas. It also provides access to consultative services that address both clinical care and biomedical ethical issues. In addition, they have developed an advance directive education packet and series of community presentations titled "My Voice-My Choice," and the Oakwood Hospital and Medical Center Guild has collaborated in this effort to empower patients and families, funding projects to increase awareness of the need for more detailed and instructive communication so patients may express their wishes for the care they receive.

Palliative care units in hospitals.

Palliative care addresses the suffering of the patient, whether physical, social, spiritual, or emotional. The provision of palliative care in hospitals and in conjunction with home hospice care assures a continuity that is important in end-of-life care. Palliative care recognizes that not everyone will die at home, nor enroll in a hospice program, and that acute care settings such as hospitals can improve end-of-life care by focusing on the relief of suffering, regardless of the disease trajectory or estimated life expectancy.

Model approaches to palliative care such as Detroit Receiving Hospital's therapeutic intervention symptom severity (TISS) scoring system provide guidance to health care providers seeking to improve the end-of-life care and demonstrate the ability to reduce costs.

Begun in 1985, the TISS system addresses end-of-life care through an inpatient, advance practice, nurse-directed system that is applied to all treatment and services the patient is receiving during a hospital stay. The program targets the patient admitted with an acute illness or injury who is not expected to survive hospitalization. However, any patient with any diagnosis has access to the program.

The TISS process includes:

- Facilitation of physician-resident identification of patients with a poor prognosis
- Facilitation of end-of-life decision making with patients or their surrogates
- Implementation of palliative care interventions when patients' care goals are for comfort only
- Facilitation of discharge to community-based hospice programs if appropriate
- Provision of psycho-emotional support to patients and their families
- Education of hospital staff.

The response of families and hospital staff to the TISS system has been positive. Outcomes include reduced use of the intensive care unit for patients who are terminally ill; reduced use of inappropriate, burdensome, or superfluous hospital interventions; reduced length of hospital stay; and reduced costs. Comparing TISS patients to all patients shows that this program saves money while improving customer satisfaction with treatment therapies. Each service is measured with all factors, including costs. TISS includes triggers that help identify when re-evaluation of therapies should occur in order to re-institute curative care. Triggers automatically start a case consultation.

Research done by Margaret Campbell, RN, in the early 1990s showed that for patients with an average of four diagnoses, health care costs were \$6,200 per day for end-of-life patients. Using

the TISS system with systemic triggers, comparable patient costs were reduced to \$2,400 per day. When families and hospital staff have been surveyed on the usefulness and effectiveness of this program, their responses have been “strongly positive.”¹

Long-term care.

Long-term care is a broad term that is applied to a variety of populations, services, and funding sources. The common characteristics include the provision of “... support services ... to people who have functional disabilities over an extended period of time, with the goal of maximizing their independence.”²

The Michigan Long Term Care Work Group identified four groups that make up the long-term care population: adults with disabilities, the frail elderly, individuals with Alzheimer’s and dementia disorders, and individuals who are at the end of life. Long-term care participants can also be defined as individuals who receive “... human assistance (hands on, supervision, or standby help) with activities of daily living or instrumental activities of daily living because of a health problem.”³

Long-term care was once understood in terms of the setting in which it occurred, which was predominantly nursing homes or similar facilities. With the development of community-based services and residential alternatives to nursing facilities (e.g., group homes, assisted living facilities), long-term care has taken on a broader meaning. Long-term care can be described as an array of settings and services that include home and community, hospitals, nursing facilities, adult day care, hospice care, and various combinations of housing and care, such as homes for the aged and assisted living programs.

Long-term care services include assistance with activities of daily living (e.g., dressing, bathing, and eating) and instrumental activities of daily living (e.g., household chores, shopping, and medication management). A person’s needs are usually met through one-on-one assistance but may also involve assistive technology (e.g., personal emergency response systems or communications devices) and environmental modifications (e.g., accessible bathroom or ramped entry). Also, informal care is a large and vital component of long-term care. In fact, most long-term care is provided by informal caregivers, that is, unpaid family members, friends, neighbors, and others. About 95 percent of elders living in the community with long-term care needs receive at least some assistance from informal providers, and almost 67 percent rely entirely on informal care.

Long-term care must also be understood in terms of its goals. Whereas the goal of acute care is curing illness, the goal of long-term care is to help improve function to some degree, or increase function to maximum independence. These goals can mean very different things across the diverse long-term care population; however, common elements of independence include exercising control over life decisions, living in the most independent setting possible, and maintaining personal security.

Under federal law, long-term care services must be covered by state Medicaid programs. The federal definition of long-term care coverage includes “nursing facility and home health services for persons age 21 and older.” Michigan’s Medicaid program within the Michigan Department of Community Health (MDCH) covers many additional non-mandatory long-term care services for

people of all ages, including the elderly, people with disabilities or mental impairment, or those with developmental disabilities. The MDCH considers long-term care as including services provided in nursing facilities, home health programs, medical care facilities, chronic care units, adult foster care homes, and personal care for in-home residents.

More than 60 percent of all reimbursement for nursing facility care in this country is paid for by Medicare and Medicaid. In Michigan, 70 percent is paid for by Medicaid, while Medicare pays for about 10 percent. In fiscal year 1998, Michigan Medicaid paid at least part of the nursing facility costs for more than 45,000 people. The long-term care policies of Medicaid are some of the most complex and expensive components of the program. The MDCH budget for fiscal 2002 was over \$8.7 billion, with Medicaid funding for long-term care exceeding \$1.4 billion. Another \$10 million was appropriated for FY 2001-02 from the tobacco settlement funds for “innovation long-term care grants”.

The challenges for design, delivery and reimbursement of long-term care services was recognized as significant, primarily because the scope and demographic trends predict continued growth of the long-term care populations (see “An aging population,” above). This group also is becoming more racially and ethnically diverse. This will no doubt have implications for the delivery of long-term care services requiring, for example, increased cultural competence among service professionals. (See also Chapter V(E), Report of the Committee on Long-Term Care.)

The Medicaid MI Choice program.

In 1992, Michigan received approval from the federal Health Care Financing Administration⁴, now called Centers for Medicare and Medicaid Services (CMS), to implement the Home and Community Based Services for the Elderly and Disabled waiver program, Michigan’s MI Choice program. MI Choice allows in-home and community services to be reimbursed by Medicaid for adults who are eligible for Medicaid-covered nursing facility services but continue to live in their own home or other residential setting in their community. In 1998, MI Choice became available in all Michigan counties. MDCH contracts with waiver agents and monitors the service providers.

People who qualify for MI Choice include those who meet financial eligibility (e.g., individuals currently on Medicaid or receiving Supplemental Security Income) and also require a nursing facility level of care. The program seeks to identify people at greatest risk for nursing facility admission, and often, participants are enrolled after a hospitalization.

MI Choice can provide 13 supportive services in addition to the full array of Medicaid benefits: homemaker services, respite services, adult day care, environmental modifications, transportation, medical supplies and equipment not covered under the Medicaid State Plan, chore services, personal emergency response systems, private-duty nursing, counseling, home-delivered meals, training, and personal-care supervision. Care management and one-on-one personal care are central to this program. The care manager helps each participant develop a plan of care that reflects his or her needs. Personal care, included in Michigan Medicaid’s State Plan, is the service most requested by MI Choice participants.

Michigan studied the importance of end-of-life issues for MI Choice participants in 1997-98. Using 1996 client tracking system data from three regions, state policymakers obtained a clearer

picture of end-of-life needs for MI Choice participants. In the regions analyzed, there were 1,462 MI Choice participants in 1996, and 236 (16 percent) of those died that year. A majority (61 percent) of those deaths occurred among participants who had been in the program for a year or less, and about half the deaths occurred among participants with less than six months' participation. The age range of those who died was 25-104, with an average age of 77.4. The average length of stay in the MI Choice program among those who died was 369 days.

According to the 222 state death records filed for the 236 people who died, 103 (46 percent) of the deaths occurred at home, 101 (45 percent) in a hospital (12 in emergency rooms), and 18 (8 percent) in nursing facilities. The causes of death reflected statewide death data: heart disease, cancer, and pulmonary diseases were the most frequently cited.

Of particular interest were MI Choice participants who died after being in the program for six months or less (117 of the 236 deceased participants). The median length of stay for this group was 77 days. The 109 available records show that 49 participants (45 percent) died at home, 50 (46 percent) in a hospital, including eight in the emergency room, and 10 (9 percent) in a nursing facility. At that time, Medicaid participants eligible for hospice care could choose either MI Choice or hospice care but not both. More than a third of the MI Choice participants who died within six months of enrolling died of cancer, a population that often uses hospice care.

The analysis resulted in Medicaid policy changes that allowed MI Choice participants access to hospice care starting in early 1999. For several years, Michigan was the only state allowing such access.

In 2000, 289 MI Choice participants statewide received hospice care. In the three regions studied and cited above, 46 MI Choice participants had received hospice services in 2000. Medicaid requires that the MI Choice and the hospice program work together, that hospice services be provided to the fullest extent before waiver services are arranged, and that there be no duplication of services.

Hospice programs.

The hospice movement began as a primarily volunteer program in England in the 1960s. Dr. Cicely Saunders developed the program to provide care and comfort to people dying of cancer. In the United States, the first hospice program began in Connecticut. Later projects were funded by the National Cancer Institute of the National Institutes of Health. With the success of these early projects and growing interest in the work of Dr. Elisabeth Kubler-Ross on death and dying, the hospice movement attained legitimacy by the early 1980s. In 1982, a hospice benefit was created in the Medicare program, and in 1986 states were allowed to include hospice care in Medicaid State Plans. Since then, the number of licensed hospice programs and the number of patients receiving hospice care have grown.

In Michigan, hospice care is now widely available. The Michigan Hospice and Palliative Care Organization (MHPCO) reports that there are more than 90 hospice programs in the state, and home hospice care is available in each of the state's 83 counties.

Hospice programs associated with the MHPCO (nearly all in the state) provide four types of hospice services, in many different settings. These services include home care, respite care,

continuous nursing care at home, and inpatient (hospital) facility care. Several hospice programs offer home-like settings in health care facilities such as hospice residences, specially-licensed nursing facilities operated by hospices, and settings such as homes for the aged and adult foster care. Seriously ill patients are thus able to receive hospice care wherever they need to live.

In 2000, Michigan hospice programs served more than 26,000 patients. There were 187 hospice-certified nurses in Michigan in 1998 and 28 palliative care-certified physicians, according to the Michigan Partnership for the Advancement of End-of-Life Care, and 44 of Michigan's 177 hospitals reported delivering palliative-care services in 1997. Still, hospice services are currently not widely used in Michigan. Hospice services are often misunderstood by health care providers, patients, and the community in general, in part because the term "hospice" implies four different definitions: a type of service, a philosophy of care, a payor for health services, and a site of care. Opportunities exist to improve the frequency of Michigan physicians recommending hospice for patients and their families to choose hospice earlier in the disease course without forcing patients to forego all curative measures, and for needed hospice services to be provided regardless of location or cost of therapy. (*See section V(C) for more details on hospice services*).

The Department of Veterans Affairs.

The federal Department of Veterans Affairs (VA) operates with the intent of maximizing each beneficiary's functional independence by offering a range of services as well as incorporating the patient's wishes into the decision-making process. The VA continually strives to integrate the efforts of beneficiary, family, and friends to assure that the veteran receives the care that will help achieve optimal healthy outcomes and quality of life. For patients receiving care in Michigan VA facilities, this philosophy aligns closely with state-funded programs that have adopted a person-centered planning approach to beneficiary care.

All VA medical centers are required to have a hospice program and a hospice consultation team in place. Within the VA hospice program, care can be provided in a variety of settings: an inpatient hospice unit, home-based primary care, or a nursing facility care unit. The VA can also contract with a community-based agency to provide hospice services. When terminally ill veterans not eligible for the Medicare or Medicaid programs request community-based hospice care, VA medical centers may need to purchase such care from a community hospice agency. Arrangements can be negotiated for inpatient care when necessary.

A VA hospice consultation team comprises, at a minimum, a physician, a nurse, a social worker, and a chaplain. The team's role is to consult with the beneficiary's primary care team on pain management and other care issues. The team recommends policies and procedures to hospital management, assumes a leadership role in promoting the hospice concepts of care, and conducts educational programs for the VA medical center and community staff. It is expected that the team will maintain expertise in the clinical care of the beneficiary and in the ethical issues involved in his or her care.

The VA covers routine, continuous, and general inpatient care under its hospice services for eligible veterans (those who have a documented service-connected illness or disability rated at 70 percent or more). Services are also provided, when clinically indicated, based on available resources, either directly or through contracts to all other eligible veterans who need or desire hospice care. Other aspects of hospice care, including room and board, are covered for eligible

veterans if the hospice services are being used at the VA medical facility. VA medical centers may provide inpatient hospice care to eligible veterans who have no caregiver or home, since these veterans cannot appropriately be referred to a community-based hospice program. Inpatient hospice beds may be located anywhere in the medical center, with care consultation and coordination provided by the hospice consultation team.

Palliative care for children.

Despite all that modern medicine has to offer, children in Michigan and across the United States experience illness and injury that limit their life expectancy. In the United States, 55,000 children die each year.⁵ Of the 86,835 deaths in Michigan in 1999, 11,603 were deaths of people less than 20 years old, reflecting a death rate of 41 per 100,000 population. Michigan's death rate for children is below the projected 2000 U.S. death rate of 43 per 100,000.^{6,7}

Since 1979, the rate of death of America's children has been declining. Much of the reduction is due to public policy efforts aimed at preventing injury and accidents; laws requiring use of seatbelts and car seats; firearm safety measures; fire and poisoning prevention initiatives; safety standards for buildings, vehicles, and consumer goods; and public health initiatives such as preventive prenatal care, well-child care, and immunization programs. In fact, the death rates of children from preventable conditions have declined by 47 percent in the past three decades.

Deaths from these preventable conditions represent slightly more than one-third of childhood death in the United States. Despite diligent efforts, 64 percent of childhood deaths are not preventable and arise from conditions such as congenital anomalies, prematurity, malignancies, neurodegenerative disease, diseases of the heart, and AIDS.⁵

In 1998-99, the Michigan infant death rate was 8 per 1000, down from about 13 per 1000 in the 1980s. Among these infants, males and females are relatively equally represented. So are black and white infants, numerically, despite the differences in population demographics. As a result, the black infant death rate is 17 per 1000, almost three times that of white infants (6 per 1000). Over age one year, males comprise more than twice the female deaths in Michigan.^{6,7}

The causes of childhood death in Michigan include, in rank order, unintentional injury, congenital health problems, cancer, homicide, and suicide. The greatest numbers of death due to homicide and suicide occur in the teen and early adult years.⁷

Comprehensive health services for children with limited life expectancy due to severe advanced illness should be available to all Michigan children. Caring for terminally ill children is an intensive, multifaceted process that requires focused management of physical, psychosocial, and spiritual issues with the clear goal of increasing child and family comfort and quality of life. In an ideal system, the unique needs of dying children and their families would be served by a combination of expertise about childhood illness available in the State's acute care pediatric institutions with the expertise about dying that exists within community hospice programs. Currently, these two entities do not routinely interact.

Hospice professionals have little experience with children. Of the 85 hospice programs surveyed by the Michigan Hospice and Palliative Care Organization (MHPCO) in 1999, 32 had no patients younger than 20 years. Of the 25,400 Michigan citizens cared for by these hospice programs in

that year, 204 (0.8 percent) were children. One hospice organization with locations across Michigan cared for 64 children in 1999, but most cared for fewer than three children that year, according to the MHPCO. Of the 16 hospice programs in the Detroit area, five have pediatric teams.

Of almost 3,000 hospice programs nationally, 22 specialize in pediatric palliative care, while 500 will admit children for care, according to a 1997 survey by the National Hospice and Palliative Care Organization. In several locations, inpatient care is available to patients who are actively dying, and for symptom management and respite for significant family stress. Palliative care consultation is available in three of Michigan's large tertiary children's hospital programs but such consultations are not always provided by pediatric specialists. At the time of this report, two Michigan pediatric physicians had completed certification in palliative care.

In 1997, the deaths of 119 children were reviewed in a study at Children's Hospital of Michigan; 22 had received hospice services, while the reviewer believed that 40 children would have been eligible and could have benefited from hospice care.

There are at least two major reasons for the lack of comprehensive palliative care for children with advanced illness. One is that childhood death is relatively uncommon and is often associated with rare syndromes, unusual defects, and unique presentations of anomalies. In all these situations, it is difficult for health care professionals to maintain expertise. Additionally, the concept of a dying child challenges our understanding of the natural order of life, faith and health, so responding to these challenges is daunting. As in situations with dying adults, health care providers involved with these patients need understand the unique challenges each patient and family presents. Have all curative options for the child been evaluated and weighed with their inherent burdens and potential benefits? How should the health care team and the family manage pain and other distressing symptoms? Who should make decisions regarding treatments, and who should manage the dying? What will the dying be like for the child? How will the family be supported through the dying and beyond?

Issues such as the child's age and stage of development and life experiences affect many aspects of the care plan, including communication methods, assessment of symptoms, determining quality of life, as well the child's actual experience of dying. There are legal and ethical issues related to individuals who are non-autonomous. There are also school and community concerns. The nature and duration of bereavement for children differs from adults, and there are different considerations and approaches for families whose children have died.

In addition, significant confusion exists, even among professionals, about which children might benefit from palliative care services. The principles of palliative care focus on the relief of suffering and attention to the best quality of life for the child and the family, consistent with the family's values, regardless of the health care setting. Many believe that these principles should be utilized for all ill children and their families and that one should not have to be dying to expect and receive this from a health care system. But there are standards of care that are emerging beyond the questions. Now the model offered by the World Health Organization, the American Academy of Pediatrics, the National Hospice and Palliative Care Organization, and others encourages offering and mixing palliative and curative services from the time of diagnosis of a life-threatening illness.^{8,9}

Currently, payment for pediatric palliative care services occurs via a variety of mechanisms. Criteria established for adult patients with specific disease trajectories are and inappropriate for children. The inclusion of curative therapies and health-maintaining services is essential in attaining the goals of treatment for the child and the family but is often problematic to health care providers and payors. Most payors place limitations on reimbursement for respite services for the care providers despite the fact that many families consider respite essential to their health, integrity, and ability to care for the dying child, siblings — and themselves. Because of the limited resources, there are those who believe there need to be changes in reimbursement policies for pediatric palliative care and hospice services and for better access to some existing sources of payment for Michigan's special needs children — which by definition include all our dying children.

The Commission supported the recommendations of the American Academy of Pediatrics on Palliative Care for Children¹⁰:

- Palliative care and respite programs need to be developed and made widely available to provide intensive symptom management and promote the welfare of children living with life-threatening or terminal conditions.
- At diagnosis of a life-threatening or terminal condition, it is important to offer an integrated model of palliative care that continues throughout the course of illness, regardless of the outcome.
- Changes in the regulation and reimbursement of palliative care and hospice services are necessary to improve access for all children and families in need of these services. Modifications in the current regulations should include broader eligibility criteria concerning the length of expected survival; the allowance of concurrent life-prolonging and palliative care; and the provision of respite care and other therapies beyond those allowed by a narrow definition of “medically indicated.” Adequate reimbursement should accompany these regulatory changes.
- All general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children. Residency, fellowship training, and continuing education programs should include topics such as palliative medicine, communication skills, grief and loss, managing prognostic uncertainty, decisions to forgo life-sustaining medical treatment, spiritual dimensions of life and illness, and alternative medicine. Pediatric board and sub-board certifying examinations should include questions on palliative care.
- An increase in support for research into effective pediatric palliative care programming, regulation, and reimbursement, pain and symptom management, and grief and bereavement counseling is necessary. The pharmaceutical industry must provide labeling information about symptom-relieving medications in the pediatric population and provide suitable formulations for use by children.
- The practice of physician-assisted suicide or euthanasia for children should not be supported.

Michigan prisons.

Since 1986, the Michigan Department of Corrections has worked with volunteers to provide hospice services to terminally ill inmates. These inmates are typically housed at the State Prison

of Southern Michigan in Jackson, where the Duane L. Waters Hospital is located and where the department has a long-standing relationship with Hospice of Jackson County.

Prisoners qualifying for hospice services must have an anticipated life expectancy of six months or less and a physician's referral, and they cannot be precluded for security reasons. A social worker interviews each eligible prisoner and matches the prisoner with a hospice volunteer, who provides end-of-life support to the inmate.

The department has been active in working with prisoners with special health care needs. The Lakeland Correctional Facility has a housing unit dedicated to inmates with special needs, many of whom are elderly. The department recognizes the importance of family visitation, especially at the end of life, and works with family members to facilitate appropriate visitation during this difficult time. In addition, in the event of a life-threatening illness or injury, family members are notified by the appropriate warden who arranges visitation in such circumstances.

Home care.

Home care includes a wide range of health and social services, delivered to people who live at home and who need ongoing care that cannot easily be provided by non-professional caregivers. Persons who are recovering from surgery or injury, individuals with disabilities, and those who are chronically or terminally ill and needing medical, nursing, social work, or therapeutic services or assistance with activities of daily living may qualify for home care services.

More and more people are choosing to live independently, and the need for home care services grows as their physical capabilities decline. Home care services are also appropriate for people of any age who have a disability or chronic illness and are able to receive complex treatments in a home care setting rather than in a hospital. The trend toward shorter hospital stays is also increasing the demand for home health services; patients are leaving the hospital earlier and may require nursing or other therapeutic interventions, such as intravenous medications.

Home care providers deliver health care and supportive services including skilled nursing care, social work services, and physical, occupational, respiratory, and speech therapies. Home pharmacy and medical equipment and supplies also fall under the category of home care services. Providers of home care services include physicians and nurses; physical, speech, and occupational therapists; social workers; home health aides; and homemakers, companions, and volunteers. Patients with advanced illness are often referred to home care for services that include end-of-life care. The challenge is to identify appropriate care for each individual. For some, appropriate care will be only restorative. For others, it is best that they be seen by palliative care or hospice specialists who can provide intense symptom management, supportive end-of-life care, and assistance with life closure. Some patients could also benefit from minimal restorative care when it has been determined that a cure is no longer an expected outcome.

Payment for home care services can be made directly by the patient or family, or through a variety of public and private sources. Commercial health insurance companies typically have home care services as part of their benefit package. Public third party payors include Medicare, Medicaid (including MI Choice in Michigan), programs funded under the Older Americans Act, and some community agencies.

C. Public and private initiatives.

Policy makers, public agencies, professionals, and the public in Michigan have all contributed to significant achievements in improving end-of-life care and planning for Michigan citizens.

The legal framework.

Legislative activity in Michigan over the past 10 years has focused on a number of issues that could improve the quality of end-of-life planning and care. Legislation has dealt with patient rights and protections, pain management, and health care decision making. Although many pieces of legislation have been proposed and passed that focus on promoting quality health care for the terminally ill, ambiguity or lack of clarity remains in some statutes and regulations, and the 2001-2002 Michigan Legislature is exploring possible statutory remedies to address health care situations involving end-of-life issues. Comprehensive summaries of statutory protections and laws exist that are intended to resolve ambiguity for Michigan citizens who want to make the best decisions for themselves and their loved ones.

Some key legislative actions in Michigan in the past 10 years are:

- Creation of the Michigan Commission on Death and Dying, 1992 (Michigan Consolidated Laws [MCL] 752.1021 et seq.). The commission was staffed by the Legislative Council, a bipartisan body that helps the Legislature research, draft, and edit bills. As directed by the statute, the commission was comprised of two members from each of 22 consumer, advocacy, and health care organizations interested in developing legislative recommendations concerning “certain issues related to death and dying.” The commission convened in July 1993 and issued its report in June 1994. The central issues the commission addressed were whether the Legislature should decriminalize assisted suicide under well-defined circumstances and whether physician-assisted suicide should, under certain conditions, be legalized. Conceptual votes on these two critical issues failed to win a majority due to abstentions, but the commission nevertheless reached consensus on several key points.

The commission recommended public education on advance health care directives, patient control over medical treatment, and the right to treatment for pain and other distressing symptoms. The commission also recommended that suicide prevention initiatives be implemented; that palliative and hospice care be made more accessible; and that the state’s Official Prescription Program be modified.

- Creation of the 17-member Interdisciplinary Advisory Committee on Pain and Symptom Management, effective June 1994 (MCL 333.16204a). This section of the Public Health Code mandates continuing education in pain and symptom management for license renewal for certain professionals: chiropractors, osteopathic and allopathic physicians, optometrists, pharmacists, podiatrists, and psychologists.

In 1998, the Legislature passed Public Act 421, which amended the Public Health Code by changing the committee’s name to the Advisory Committee on Pain and Symptom Management, with 15 members. Codified as MCL 333.16204 (a), (c), and (d) and effective in April 1999, it also defined “intractable pain” and updated the requirement for pain

management education to include annual reports to the directors of the state departments of Consumer and Industry Services and Community Health on pain education.

- Dignified Death Act (MCL 333.5651 et seq.). This law was written in 1996 to respond to the unique needs of patients who have been diagnosed with a terminal illness. It ensures that these patients are properly informed about their rights and options.
- Designation of Patient Advocate (1998; MCL 700.5506 et seq.). A patient advocate is a person who has been named by another individual to make health care decisions when the latter can no longer speak on his or her behalf. This designation covers not only end-of-life decisions, but also any situation in which the patient is unable to participate in a health care decision. This law recognizes the rights of the patient to appoint a surrogate decision-maker and to give instructions about the type of care the person would accept or reject when the person cannot participate in medical decision-making.
- Do Not Resuscitate Procedure Act (1996; MCL 333.1051 et seq.). This law recognizes the right of individuals who do not wish to undergo extraordinary efforts to prolong their life to refuse the services of emergency medical services responders after their heart and respirations stop. Those who wish can sign a Do Not Resuscitate (DNR) Order, which will tell others not to begin cardiopulmonary resuscitation. Another means of revealing this decision is for a person to wear a bracelet, available from any hospice program in Michigan that indicate to responders that the DNR order has been signed.
- Patient and Resident Rights and Responsibilities (1978; MCL 333.20201) are contained in the Michigan Public Health Code and are related to individuals participating in medical decision-making. In summary:
 - Patients have the right to accept, reject, or discontinue medical treatment.
 - Patients have the right to informed consent.
 - Patients have the right to information about state laws concerning treatment.
 - Terminally ill patients have the right to be informed about and to be offered an opportunity to choose palliative care.
 - Patients have the right to file complaints about care and treatment.

Public efforts.

Public efforts have been under way for years to help people who have questions, need resources or information, or are seeking referrals for appropriate end-of-life services. The ultimate goal of public policy and legislation is the assurance that individual decisions are made with all pertinent information at hand that will improve the quality of care received by individuals at the end of their lives.

MDCH has been working energetically to ensure that people are aware of their rights, new and old, and that resources are available to improve end-of-life planning and care. MDCH does not intend to become a center of excellence for end-of-life education but has been facilitating and supporting a variety of efforts to position Michigan as a leader in the field. These include:

- Michigan Circle of Life. Formed in 1997 to focus on preserving the dignity and rights of terminally ill and chronically ill people in Michigan, this coalition is comprised of

professional associations; organizations of care providers; education, religion, and advocacy groups; and others. Meeting each year, the Circle of Life has emphasized increasing public awareness of hospice care and the special rights that all citizens have at the end of life. By using public service announcements (PSAs), the Circle of Life has successfully advertised a toll-free public information hotline that has continued operation. By working with the Michigan Association of Broadcasters, member radio stations have benefited from a bonus incentive program such that \$65,000 allocated for hospice PSAs resulted in \$375,000 in actual advertising time.

The group has set priorities for its activities that include:

- Support of programs that focus on individual dignity and quality of care for people with terminal illness
- Programs serving people with chronic illnesses to reduce the rate of suicide through greater knowledge and use of improved pain management
- Education for health care practitioners and faculty in managing pain and providing palliative care and suicide prevention.

Since its inception, the Circle of Life has been involved in activities such as:

- Palliative care education and other continuing education for physicians, nurses, and nurse aides
 - Funding and distribution of an interactive CD program, “Easing Cancer Pain”
 - Disseminating information about resources that exist to help make decisions about end-of-life issues such as the Michigan Dignified Death Act, the Michigan Patient Bill of Rights, hospice services, the Durable Power of Attorney for Health Care process, and other tools.
- A toll-free public information phone line. MDCH has been funding a toll-free referral phone line that provides information and education about hospice and end-of-life care to the general public and providers. Callers can request an information packet containing a collection of materials that are designed to address end-of-life issues in a clear, understandable and non-threatening manner. Public response to this service, which has been available since 1997, has been favorable.
 - The Michigan Partnership for the Advancement of End of Life Care. In early 2000, the Michigan Partnership for the Advancement of End of Life Care received a three-year, \$450,000 grant from the Robert Wood Johnson Foundation to research three key areas of end-of-life care. The project strives to “improve the quality of care that individuals and their families can expect at the end of their lives.” Comprising more than 30 Michigan organizations and associations, including the Michigan Department of Community Health, the grant is administered by the MHPCO. The project began in January 2000 and is supported by in-kind contributions from its members. One group was formed to address each of three areas of end-of-life care:

Professional education. This team is addressing the end-of-life care needs of medical, nursing, pharmacy, social work, and pastoral care students in Michigan. After collecting information on the curricula of each profession, an interdisciplinary team will make recommendations for improvements that will be disseminated for implementation.

Nursing facilities. This team is focusing on helping Michigan nursing homes provide better care, particularly pain management, for their residents. They are implementing a staff training program in six facilities using the American Medical Directors Association's pain management clinical guidelines. Then each facility's staff will develop training plans tailored to their needs, with recommendations for duplication on a statewide basis.

Community resources. This group is focused on the information needs of underserved populations in the end-of-life arena. They have held community focus groups with four populations: rural native Americans, rural whites, urban African-Americans, and Spanish-speaking Latinos. The focus groups were facilitated by community leaders, who also helped recruit participants.

The work of the Partnership for the Advancement of End of Life Care also involves oversight, including site visits by the national program office, annual meetings, and production of a final report with recommendations, expected to be released in late 2003.

Some outcomes of this work include:

- More research-based knowledge about end-of-life care
 - Proof that flexibility in treatment modalities can be successful
 - Greater access to palliative care for many more patients versus the limitations inherent in the traditional hospice services
 - Appropriate reimbursement from third party payors.
- CD-ROM interactive series on pain management. There are two Web-based interactive consumer resource projects to help patients learn more about end-of-life care, pain, treatment of pain, spiritual issues, grief, and advance directives. Both projects were funded by MDCH and the Henry Ford Health System and a grant received from the Robert Wood Johnson Foundation, the Cancer Center at Michigan State University, and royalty income from sales of the CD ROMs.
 - Twelve thousand CDs entitled "Easing Cancer Pain" were produced and distributed to public libraries, nursing facilities, and other consumer access sites identified by MDCH.
 - The second CD-ROM, "Completing a Life", is a rich resource featuring easy-to-use navigation tools that allow the user to chart a personal pathway through more than one hundred separate topic pages. In addition, some pages link to special topics designed primarily for family members and to further resources on the Internet.

The material contained in *Completing a Life* covers a wide range of concerns, addressing such areas as getting good pain relief, talking with health professionals, family communication, writing advance directives, and finding answers to spiritual questions. It contains three main content areas:

- Taking Charge – staying active in decisions about health care, family, and everyday living
- Finding Comfort – easing pain and suffering, and living with dignity at this time of life

- Reaching Closure – coming to terms with the past, present and future, and exploring the possibilities for spiritual growth.

Along with the text material is a section devoted to the Personal Stories of nine diverse individuals who describe how they have faced the challenges of terminal illness. These video narratives illuminate many of the topics addressed in the content sections and are extensively cross-linked with the text to enhance the user's interactive, multimedia experience.

- Research pilot hospice residency program. For several years, the Michigan Legislature has funded hospice and palliative care initiatives. One of these, the "Hospice Residency Research Project," was a pilot project to assess the long-term feasibility of paying the cost of room and board in a licensed hospice residence for individuals who qualified for hospice care and were low-income, some with Medicaid eligibility. The individuals participating could not remain at home, or did not have a home, or did not need or want to move into a nursing home. Because Medicaid (and Medicare) cover only hospice costs and not housing costs, this project sought to demonstrate savings to the state by allowing the patients to remain in the residence and avoid a nursing home stay that may eventually be paid by Medicaid. Insufficient numbers of participants caused the results to be insignificant.
- Long-Term Care Work Group. In March 1999, the Michigan Long-Term Care Work Group was established. Its members were four state legislators, appointed by the speaker of the House of Representatives and the Senate majority leader, and four leaders from MDCH, appointed by Director James K. Haveman, Jr. The group held a series of meetings and hearings and in June 2000 produced a final report that included recommendations in the areas of quality of life and quality of care, personal responsibility, living independently, eligibility, nursing homes of the future, and organized systems of care. Several state regulatory and statutory changes were proposed and implemented within months of the report's release. The report recommends the establishment of four different long-term care models to provide integrated and coordinated services to eligible individuals.
- Long-term care innovations grants. In recognition of the need to foster the development of long-term care innovations as envisioned by the 1999 Michigan Long Term Care Work Group in fiscal year 2001, the Michigan Legislature appropriated \$10 million one-time funding in Tobacco Settlement funds to support program development. A competitive process to allocate \$7.4 million of the funds was established, and more than 200 proposals were received from across the state. MDCH reserved the remaining \$2.6 million for start-up and evaluation activities to implement the models of long-term care delivery described in the work group's final report and to conduct projects already approved by the work group.

Finally, the Michigan Department of Consumer and Industry Services:

- Assures standards are met through licensing and inspecting facilities and providers such as hospitals, hospice programs, nursing homes, and individual providers.
- Works with the MHPCO to encourage appropriate pain management in end-of-life care.
- Through the Quality Improvement Nurse Consultation Program, is developing training programs to promote best practices in long-term care facilities related to pain management and other end-of-life care issues.

- Serves as a resource to hospice programs for information on medications and pain management.

Private organizations.

Michigan Hospice and Palliative Care Organization. The purpose of the MHPCO is to serve as an advocate for all terminally ill people in Michigan by working to provide equal access to quality hospice and palliative care for all Michigan citizens. The MHPCO represents the more than 90 hospice programs statewide and works with them to use education and the public arena to assure continuing improvement in end-of-life care. Active in Michigan and nationally, the MHPCO is supported by hospice programs, physicians, business organizations, and individuals who believe in its work.

The MHPCO was founded in 1979, and its first purpose was to promote the development of hospice programs in Michigan. Early staff and volunteers made themselves available to communities throughout the state, assisting local leaders with the organization of hospice programs. Today, every county in Michigan has at least one hospice program serving its citizens, and many counties have several available. Early MHPCO members worked with start-up hospice operations to make sure that the standards and practices for the delivery of hospice care in Michigan were at the highest level possible, a task the organization still pursues.

The MHPCO currently manages two referral programs for the public and for hospice patients. The previously mentioned toll-free phone line helps patients and families find hospice care and get answers to questions about such care. The Hospice Legal Aid Program uses volunteer attorneys to help dying patients who cannot afford an attorney, address basic end-of-life legal concerns. The MHPCO has participated in national programs such as the Annenberg Project, designed to assist physicians in the communication of issues related to end-of-life communications. The MHPCO Hospice Medical Directors Division convenes a clinical staff day each year for clinicians committed to the care of the terminally ill. The MHPCO also supports the efforts of the state's two physician groups, the Michigan State Medical Society and the Michigan Osteopathic Association.

Additionally, the MHPCO is administering several major grant projects intended to improve the care of the dying in Michigan. Discussed in more detail in "public efforts", The Michigan Partnership for the Advancement of End of Life Care is funded by the Robert Wood Johnson Foundation and includes three projects designed to identify activities in long-term care, health professional pre-degree education, and community resources that will foster better attention to the needs of seriously ill patients and their families. Another project, funded by the Granger Foundation, provided support as the MHPCO developed a website for public information and referral purposes.

The MHPCO works in concert with the National Hospice and Palliative Care Organization to address public policy needs on the national level, with particular attention to Medicare issues and the concerns of the federal Centers for Medicare and Medicaid Services. The organization is also active on a state public policy basis, working with MDCH and the Department of Consumer and Industry Services to change the systems where needed and feasible, to allow for improvements in the care of the dying in Michigan.

Originally called the Michigan Hospice Organization, MHPCO changed its name in 1999 to publicly announce its work in activities related to the delivery of palliative care earlier in the disease process.

Michigan Health and Hospital Association (MHA). In June 1998, the MHA created a Task Force on End-of-Life Care that was charged to:

- Identify existing and needed services and resources, as well as barriers to accessing end-of-life care
- Create a tool to help members assess their communities' needs and available resources to better meet those needs
- Identify providers and communities that have developed best practices and share that information with members.

The task force formed subcommittees on professional issues; patient, family and community issues; and regulatory, legislative and reimbursement issues. The group made the following recommendations to the MHA, which were subsequently approved by the MHA board:

- Link with other statewide groups and ongoing efforts to address end-of-life care issues. The goal was to maximize impact and minimize duplication and to promote the development of common programs and projects.
- Identify funding sources and work with other groups to obtain funding to improve end-of-life care; actively participate in the statewide Robert Wood Johnson Foundation partnership program.
- Take a leadership role in promoting the development of a statewide coalition of providers and other agencies in each Michigan community or region to catalog available services, resources, and programs and make that information publicly available on a state-wide Web site; identify an appropriate organization to oversee, maintain, update and promote the Web site; help communities identify gaps in services and develop community or regional plans to fill those gaps.
- Collaborate with professional organizations and law enforcement agencies, including the Michigan attorney general and prosecutors, to provide education on appropriate pain management practices to assure that patients receive the pain control they need and that physicians are not subject to unwarranted fear of prosecution.
- As part of the MHA's Healthy Communities initiative, create a means to identify the best practices among health care organizations and professionals and disseminate this information.

Detailed findings are contained in the task force's final report, "A Call for MHA Member Leadership." The task force also developed a community needs assessment tool to be used by providers and communities in identifying existing and needed community end-of-life resources.

Physician organizations. Both major physician organizations in Michigan have been active in end-of-life issues. The Michigan State Medical Society (MSMS), an association of 14,500 medical doctors licensed in Michigan, has been actively involved in end-of-life issues for decades, including hosting a 1991 statewide forum to discuss ethical issues related to the emerging issue of physician-assisted suicide and to discuss ways to improve end-of-life care that might help deter patient requests for assisted suicide.

The MSMS established a Committee of Hospice Medical Directors in 1996 to help promote the use of hospice care in Michigan. In 1998, the MSMS created a Task Force on End-of-Life Care to take a multi-disciplinary approach to the issue and develop short- and long-term goals and objectives. The Task Force focused on physician and patient education. Various continuing medical education courses on end-of-life care have since been offered to physicians at conferences throughout the state and at the MSMS Annual Scientific Meeting.

In 1999, the American Medical Association chose more than 200 U.S. physicians to undergo a rigorous curriculum in state-of-the-art palliative care. Fifteen were from Michigan; they brought information from this train-the-trainer program back to Michigan and, by 2001, had educated over 50 additional physicians through courses organized by the MSMS and supported with a grant from MDCH.

In 2000, the MSMS collaborated with the other major physician organization in the state, the 3,300-member Michigan Osteopathic Association, and the physician insurer American Physicians Assurance to develop a booklet called “The Michigan Physician Guide to End-of-Life Care.” The booklet contains medically concise “how-to” instructions and pages that can be duplicated and given to patients and families, and lists Web sites and other resources. The booklet, also funded by MDCH, gained national attention after its release in September 2001. Its first printing of 40,000 was distributed to all licensed Michigan physicians, medical residents and medical school students, many hospitals, nursing homes, and others interested in an excellent end-of-life care resource.

Community-based efforts. One Michigan community-based group will stand as an example of the good that can grow out of sustained, community-based concern about end-of-life issues.

The Traverse Area Coalition for Dignity at the End of Life was formed in 1999 to strengthen the community’s ability to meet the needs of citizens for care at the end of life in a positive and meaningful way. With leadership from the Munson Medical Center, the Hastings Center, and regional health care systems serving northern lower Michigan and the eastern Upper Peninsula, coalition membership includes more than 100 individuals and provider organizations.

The goals of the coalition include assessing communities’ needs; identifying barriers to good end-of-life care; encouraging communities to act to improve services and to increase access to them; providing a mechanism for community members to take part in problem-solving; sharing resources and expertise within the community; and evaluating its own actions so as to be able to improve efforts in the future.

A broad cross-section of the community is working to “hear the voices and honor the choices” of individuals. A community survey and needs assessment has been completed; results have made it possible for leaders to modify existing programs and plan initiatives that more closely meet the expectations of community members. Task forces have been created to address the issues of palliative care resources, caregiver support, and increasing participation of citizens in advance care planning.

With the leadership and resources of the coalition, individual health providers such as the Family Practice Pilot Program are working to increase utilization of advance care planning tools by their

patients. Many coalition members believe that the interest and energy created by its activities will stimulate the demand for improved services and help sustain ongoing initiatives to improve care of the dying throughout the region.

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V. Committee reports and recommendations

- A. Professional education.**
- B. Pain and symptom management.**
- C. Reimbursement.**
- D. Long-term care.**
- E. Decision-making for the end of life.**
- F. Family issues.**

V(A). Professional education.

Access to effective end-of-life care requires health care professionals who are educated to deliver it. While efforts are under way in some medical and nursing schools to educate students in the basic elements of palliative care, comprehensive end-of-life care curricula are the exception.¹ The Commission's Professional Education Work Group sought to evaluate the adequacy of Michigan health professional education, residency instruction, and continuing education programs and to recommend improvements. To accomplish this, the work group assessed the effectiveness of continuing education; and, in coordination with the Michigan Partnership for the Advancement of End of Life Care, sought more information on the state of end-of-life education in five health disciplines in Michigan's schools and programs; and surveyed Michigan medical residency programs. While the survey of residency programs was limited to medical school education, the results are suggestive of needs in other health professional disciplines. Further work in other disciplines is ongoing as part of the Michigan Partnership for the Advancement of End of Life Care Professional Education Project, with the final report expected in 2003.

The American Association of Medical Colleges, in its Medical School Objective Project, concludes that there is a lack of consistent, effective curricula in end-of-life care in U.S. colleges of medicine. According to its 1998 survey, fewer than 40 percent of medical schools offer an elective course that deals with palliative care, and an even smaller proportion have made such a course a requirement. While nearly every school curriculum touches on death and dying, treatment of the subject often comprises a single lecture, a brief class discussion, or assigned readings. As a step toward more effective education and education of medical students in compassionate care at the end of life, the Medical School Objective Project established national educational standards and objectives for end-of-life curricula.²

An effort already discussed (see IV C Public and private initiatives) and with similar objectives is under way in Michigan. Called the Michigan Partnership for the Advancement of End of Life Care, it is supported by grant from the Robert Wood Johnson Foundation. Now in the second year of a three-year project, the partnership is evaluating the state of professional education among Michigan schools of medicine, nursing, pharmacy, social work, and pastoral care. To date, the project is both revealing and encouraging significant efforts to develop and implement innovative and effective end-of-life curricula in Michigan's health professional education programs.

Medical, nursing, and social work education.

Medical education. In medical education, for example, Michigan's four colleges of medicine (at the University of Michigan, Wayne State University, and the College of Human Medicine and the College of Osteopathic Medicine at Michigan State University) have undertaken to share curricular resources and coordinate efforts in curriculum and faculty development. All four report significant curricular attention to end-of-life care. One requires a hospice rotation as part of an outpatient clinic rotation. Two have required curriculum in end-of-life care issues. Through the development of core competencies in pain and symptom management, palliative care, patient and family issues, attention to the organization of care and the health care professional's role, and psychosocial care of the dying, these medical curricula are introducing a new generation of physicians to the elements of end-of-life care.

Nursing education. The nursing profession's commitment to care of the dying and terminally ill is evident in many different initiatives. Nurses and nursing organizations have a breadth of experience, knowledge, and skills related to end-of-life care. Many nursing organizations have developed educational programs, position statements, policies, guidelines, research projects, and compassionate care agendas to improve the care of dying patients and their families.³

In January 1999, the Open Society Institute, through its Project on Death in America (PDIA), funded the Nursing Leadership Consortium on End-of-Life Care. The consortium was developed to help advance the nursing profession's commitment and efforts to improve care at the end of life.⁴ It brought together national nursing organizations with education, administration, research, practice, and policy responsibility and specialty organizations with particular expertise in end-of-life care to develop a coordinated, broad-based plan within the profession to improve end-of-life care. The specific aims include:

- Formalizing a collaborative and supportive effort within the profession focused on end-of-life care
- Examining educational materials, clinical guidelines, and other material on end-of-life care currently available in nursing
- Developing mechanisms of collaboration and resource sharing among nursing organizations
- Identifying gaps and future needs within the policy research, education, administration, and practice domains of nursing.

The consortium, nursing organizations and educators identified many barriers that exist in end-of-life care and are committed to improving this area of nursing practice within current nursing education. As a result, several initiatives (the Project on Death in America, Robert Wood Johnson Foundation, and others) are under way across the country to improve the educational and clinical outcomes of end-of-life care and to identify and endorse specific standards and competencies that involve nursing care for the dying.⁵

In assessing the state of end-of-life care education in Michigan's six schools of nursing (at Grand Valley State University, Lake Superior State University, Madonna University, Michigan State University, Oakland University, and the University of Michigan), the Michigan Partnership for the Advancement of End of Life Care examined the curricula of 15 identified competencies that nurses need in order to provide high-quality end-of-life care to patients and families. Their assessment found that these schools offer from four to 15 courses (with an average of eight) addressing end-of-life care. A majority of these courses are required. Most schools offered some curriculum to address each of the identified competencies.

Social work education. The Partnership has also assessed the state of end-of-life care education in the 16 bachelor of social work (BSW) programs in Michigan. Only four offer curricula designed to address end-of-life care, all in elective courses. This implies that little explicit attention is given to end-of-life care in social work education. This may be due, in part, to the demands that curricular structures follow accreditation guidelines. There may also be some concern that BSW programs are generalist in nature and are not flexible enough to educate by specialties. More than two-thirds of the program directors said they felt that inadequate attention is given to end-of-life care curriculum.

Table 5(A)1 – Availability and adequacy of education in three general areas as self-reported by medical residency and fellowship programs in Michigan.

	End-of-life care	Pain/symptom management	Hospice care
Any formal training	46% (88)	56% (107)	31% (59)
Required formal training	32% (62)	40% (77)	20% (39)
Required clinical formal training	14% (26)	18% (35)	12% (23)
Adequacy of training:			
Excellent	16% (31)	23% (45)	11% (22)
Adequate	54% (104)	51% (97)	46% (89)
Inadequate	20% (38)	13% (24)	28% (54)

N=192

Table 5(A)2 – Availability of education in specific areas in medical residency and fellowship programs in Michigan.

	Required of all residents	Electives offered	Not included in program
Pain management	65% (124)	15% (28)	20% (38)
Control of symptoms other than pain	63% (120)	6% (12)	21% (41)
Determining prognosis	63% (120)	6% (12)	23% (45)
Spiritual needs assessment	22% (42)	11% (21)	58% (112)
Insurance regulations related to hospice care	15% (29)	9% (17)	66% (126)
Bereavement care	33% (63)	9% (18)	50% (96)
Care of the family of the dying patient	40% (77)	10% (19)	44% (85)
Home care for dying patients	28% (53)	12% (23)	51% (97)

Postgraduate education.

There is considerable evidence that physicians are not well educated in end-of-life care. Other evidence suggests that residency is an important stage of professional experience since it is a formative period for clinical identity and a time during which practice patterns are established that are apt to last a lifetime. Furthermore, studies conducted in the past 25 years indicate that continuing medical education does not have a significant, lasting effect on either physician behavior or patient outcomes.⁶

Finding a lack of reliable data regarding postgraduate medical education, the Work Group undertook a comprehensive survey of residency and fellowship programs in Michigan. This study examined the self-reported instruction in end-of-life care, pain management, and hospice care in all postgraduate medical education (both residency and fellowship) programs in Michigan. The survey instrument, a mail survey of 275 residency and fellowship directors identified by the American Medical Association, was designed after a literature review and interviews with experts in the field. It was then pilot-tested with four former residency program directors, and their suggestions were incorporated into the revised instrument. The instrument identified the specialties available at each institution; the extent of education provided in end-of-life care, pain management, and hospice care; whether those courses of study are required or

Table 5(A)3 – Availability and adequacy of education in three general areas as self-reported in primary-care specialties by Michigan medical residency and fellowship programs.

	End-of-life care	Pain/symptom management	Hospice care
Any formal training	82% (41)	76% (38)	70% (36)
Required formal training	58% (29)	56% (28)	52% (26)
Required clinical formal training	38% (19)	16% (8)	44% (22)
Adequacy of training:			
Excellent	24% (12)	24% (12)	22% (11)
Adequate	62% (31)	62% (31)	58% (29)
Inadequate	14% (7)	14% (7)	20% (10)

N=50

Primary care was defined as family practice, internal medicine, pediatrics, geriatrics, and internal medicine/pediatrics.

Table 5(A)4 – Availability of education in specific areas as self-reported in primary-care specialties by medical residency and fellowship programs in Michigan.

	Required of all residents	Electives offered	Not included in program
Pain management	84% (42)	18% (9)	6% (3)
Control of symptoms other than pain	76% (38)	10% (5)	10% (5)
Determining prognosis	74% (37)	8% (4)	16% (8)
Spiritual needs assessment	42% (21)	12% (6)	46% (23)
Insurance regulations related to hospice care	36% (18)	12% (6)	50% (25)
Bereavement care	54% (27)	10% (5)	34% (17)
Care of the family of the dying patient	68% (34)	12% (6)	18% (9)
Home care for dying patients	64% (32)	18% (9)	14% (7)

elective, and what form they take; and the respondents' overall evaluation of these curricula at their institutions. (The survey instrument appears as Appendix VII(D)2).

Of those surveyed, 192 (70 percent) returned useable surveys; 50 (26 percent) of the respondents were from primary care programs, and the others represented a broad range of specialties. The results of the survey are illustrated in Tables 5(A) 1-6.

Fewer than one-third (30.7 percent) of respondents reported any formal instruction in hospice care. Fewer than half (45.8 percent) reported formal education in end-of-life care, while slightly more (55.7 percent) reported formal course work in pain management. Primary care programs appear to devote significantly more time on end-of-life education than other areas, with more than 80 percent reporting formal training in end-of-life care, 75 percent in pain management, and 70 percent in hospice care.

This study provides a brief snapshot of the state of post-graduate medical education in Michigan. It reflects considerable variation, among primary-care programs and other specialty programs, in

instruction in hospice care, pain management, and end-of-life care. In contrast to the rather dismal

Table 5(A)5 – Availability and adequacy of education in general areas in non-primary-care specialties as self-reported by medical residency and fellowship programs in Michigan.

	End-of-life care	Pain/symptom management	Hospice care
Any formal training	33% (45)	49% (69)	18% (25)
Required formal training	24% (33)	35% (49)	9% (13)
Required clinical formal training	12% (16)	26% (36)	6% (8)
Adequacy of training:			
Excellent	13% (18)	24% (33)	8% (11)
Adequate	53% (72)	46% (65)	42% (59)
Inadequate	22% (30)	12% (17)	31% (44)

N=140. Primary care was defined as family practice, internal medicine, pediatrics, geriatrics, and internal medicine/pediatrics.

Table 5(A)6 – Availability of education in specific areas in non-primary-care programs at medical residency and fellowship programs in Michigan.

	Required of all residents	Electives offered	Not included in program
Pain management	59% (81)	14% (19)	24% (33)
Control of symptoms other than pain	59% (81)	5% (7)	25% (34)
Determining prognosis	59% (82)	5% (7)	26% (36)
Spiritual needs assessment	15% (21)	10% (14)	63% (87)
Insurance regulations related to hospice care	8% (11)	8% (11)	71% (98)
Bereavement care	26% (36)	9% (12)	56% (77)
Care of the family of the dying patient	27% (37)	9% (12)	54% (74)
Home care for dying patients	15% (21)	9% (13)	64% (88)

picture painted by limited earlier evaluations of postgraduate education, this study demonstrates some improvement in Michigan programs. However, both the hard data and the nature of the participants' comments in this study suggest that there is a great deal of room for more improvement, both in terms of program content and in terms of attitude. For example, a number of residency directors reflected a certain complacency when they rated the adequacy of their programs high — even while reporting that they had no instruction in a particular area. Future studies must assess postgraduate education more rigorously than is possible in a self-report study.

Recommendations.

The Commission makes these recommendations for the undergraduate, graduate, and continuing education of those engaged in the delivery of health care and related services in Michigan.

- 1 Health professional schools or programs should include in their core curriculum for all students the core content of end-of-life care appropriate to their discipline, including knowledge, skills, and attitudes. They should regularly assess and evaluate end-of-life care content, both didactic and experiential, in their curriculum. This assessment should include consideration of the professional expertise of faculty involved in end-of-life care education.
- 2 Each professional school or program should work collaboratively with other schools within its discipline and within its larger educational institution to enhance the overall quality of training in end-of-life care.
- 3 Each professional school or program should specifically charge at least one faculty member with developing and coordinating a curriculum that appropriately addresses end-of-life care. This role should be explicitly recognized in the institution and in the faculty members' responsibilities and dedicated time. Professional schools and programs should support faculty development in end-of-life care, capitalizing on the expertise of community professionals experienced in hospice and palliative care.
- 4 The Michigan Department of Community Health (MDCH) should take a leadership role in exploring options for end-of-life care education innovation grants to support curriculum assessment, development, and evaluation by individual schools and programs, as well as the development of interdisciplinary and inter-institutional efforts to improve the quality of end-of-life education.
- 5 MDCH should explore possibilities for making financial grants available to students enrolled in health professional schools or programs who are committed to end-of-life care.
- 6 MDCH, the Michigan Department of Consumer and Industry Services (MDCIS), and all applicable health profession licensing boards should promote and advance the art and science of end-of-life care in education of all health professionals at all levels of instruction, certification, and licensure in order to ensure the highest quality of end-of-life care for all Michigan citizens, and should promote palliative care as a defined area of expertise, education, and research.
- 7 In light of the Commission's finding that the current model of didactic lecture-based continuing medical education is not effective in changing the behavior of practicing physicians, the institutions providing education in health care and related specialties should develop new models of highly interactive, case-based, patient-focused education that incorporate adult learning principles to improve the abilities of physicians and other health care professionals as they care for people who are dying. The appropriate health profession licensing boards and MDCIS should change the continuing education requirements for re-licensure accordingly.

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V(B). Pain and symptom management.

This committee studied the ability of individuals in Michigan to obtain effective pain management as part of end-of-life care. The study includes consumer, professional, institutional, and distribution issues and the effect of applicable regulatory programs on access to effective pain management.

Findings.

The committee found a broad consensus that the management of patient pain and symptoms is inadequate in Michigan. Michigan citizens therefore endure undue suffering, which affects their end-of-life care. The evidence supporting this consensus comes from many sources and perspectives. Many people, including health care professionals, administrative personnel, people with expertise in end-of-life issues, patients, and families, spoke at the five public hearings that the Commission held in September 2000. Others provided written testimony and reports to the Commission.

The committee also learned that:

- Pain is a highly personal and subjective experience. The appropriate treatment of pain depends on what is causing the pain. Research, including studies of pain experienced by hospitalized patients within the last weeks of life¹, confirm the undertreatment of many kinds of pain in a variety of settings. Pain can result from the disease process itself or from diagnostic and therapeutic medical procedures and treatments or conditions not related to the life-limiting illness.²
- Vigilant attention to physical and emotional symptoms is the core of high-quality end-of-life care. Although measures to treat pain may be both pharmacological and non-pharmacological, medications are the cornerstone of good pain management programs. Pain management includes facilitating optimal comfort, functional ability, and quality of life as the individual defines it.²
- Many different classes of medications are employed and are effective for the treatment of pain.³ Current medications have both beneficial symptom-relieving effects and negative or complicating effects. Appropriate treatment must evaluate and balance all of these for each individual patient by maximizing the effects that are desired and minimizing those that are not. Even within a class of medications, some are more effective than others for the treatment of pain, and some have significant side effects that limit their use despite effectiveness.

The focus of this report is on pain at the end of life and on the underutilization of opioid medications for the treatment of pain. Some of the findings relate to pain in general, others specifically to pain at the end of life. All the issues related to opioid use are relevant to patients, providers and regulators in Michigan. Many classes of medications besides opioids are used in the treatment of pain syndromes, and it is not the intent of this report to diminish their importance in pain management. However, the Committee on Pain and Symptom Management believes that the single most effective and underutilized class of medication for the treatment of pain at the end of life is the group of opioid analgesics. These will be the focus of the committee's comments.

It is recognized that many regulators and even some clinicians consider the Schedule III⁴ opioid agents to be safer than Schedule II opioids because they are less highly regulated; however, Schedule III drugs are often less effective at treating pain and more prone to having negative emergent effects, such as nausea, liver or kidney toxicity, or gastric complications, that greatly impair their utilization as medications of choice.^{5,6,7}

- Data indicate and experts agree that early and aggressive pain treatment lengthens and improves the quality of life, although this is contrary to what many patients, families, and even some physicians assume.^{2,8,9,10} Michigan citizens and health care practitioners should be well informed about effective pain management. Policy-makers and clinicians must be aware of both the positive and negative consequences of pain medications currently being used and understand how the regulatory system could and should be structured to encourage safe and effective use of drugs and other modalities to treat pain.
- The Federal Controlled Substances Act (21 US Code, Section 823(a)(1)) and the Michigan Public Health Code [Michigan Compiled Laws (MCL) 333.16204c(1)] both require a balanced approach to controlled substances, with attention to: 1) availability and use of safe and effective drugs for legitimate medical purposes, including pain management; and 2) an ability to detect and control diversion of prescription drugs for illegal use. The committee believes that Michigan's system as it currently functions lacks the intended balance. Michigan needs a balanced program that effectively uses the resources of an electronic or other tracking system that is efficient, invisible to the patient and practitioner, and provides information that is well understood and readily available to those who need it.^{11,12,13,14,15} The Official Prescription Program (OPP) currently is a costly system that tracks only one category of controlled substances and has little effect either on good pain practice or on detecting and preventing drug diversion.^{16,17} It also causes some prescribers to think, mistakenly, that they are at risk if they prescribe Schedule II opioids.¹⁸

Recommendations.

The Committee on Pain and Symptom Management makes the following recommendations:

1 The Governor and Legislature should declare that lack of effective pain management is a public health issue that requires the highest level of professional and regulatory attention. The Governor, the Michigan Department of Community Health (MDCH) and the Michigan Department of Consumer and Industry Services (MDCIS) should initiate a statewide awareness and educational campaign targeted to the public and health care professionals that includes public service announcements and informational hotlines about issues related to pain and symptom management.

Rationale.

Testimony presented at the Commission's public hearings indicated that significant numbers of patients, caregivers, and professionals see effective pain management as one of the most elusive goals in health care for Michigan residents. Patients and their loved ones often think pain is an uncontrollable element of the patient's underlying condition.¹⁹

In a community survey from the Traverse City area, according to Kay Benisek of the Traverse Area Coalition for Dignity at the End of Life, more than 700 respondents felt that physical comfort and freedom from pain at the end of life was very important to them; 99 percent wanted freedom from pain. Still, what these Michigan citizens want and what they expect are very different: 51 percent believe their physician will not treat their pain; 56 percent believe it is easy to become addicted to pain medication; 41 percent feel it is easier to put up with pain than deal with the side effects of pain medication; and 61 percent believe that it is important to take as little pain medication as possible and to save larger doses for later, when the pain becomes more severe.²⁰

A 1996 study of patients at the Detroit Medical Center found that patients rated the worst pain they had experienced in the previous 24 hours at 7.2 on a scale of 0-10.²¹ Another study indicated that 45.3 percent of the 50,321 patients in Michigan nursing homes in 1999 reported having pain and for 9.2 percent of those with pain, it was excruciating pain; when the patients with pain were resurveyed at least 60 days later, 39.2 percent had worse pain or their pain remained at a severe level.²² In a 2000 study conducted by the Michigan Hospice and Palliative Care Organization, hospice directors estimated that more than one-third of hospice patients are admitted with severe or uncontrolled pain.²³ In short, recent studies of Michigan hospitals, nursing homes, and hospice programs are consistent in their documentation of high pain levels among Michigan residents who are admitted to health care facilities.

The committee found that Michigan professionals have a serious lack of understanding of the principles of effective pain management. These knowledge and practice deficits were identified again and again in public hearing testimony received by the Commission across the state.¹⁹

Effective management of pain and distressing symptoms should include both pharmacological and non-pharmacological modalities; however, the effective use of medications is the cornerstone of good pain management. When properly prescribed and administered, opioids are highly effective and essential therapies for the management of pain. They are frequently the drugs of choice.^{2,8}

Opioids are listed by the federal Food and Drug Administration and the State of Michigan in either Schedule II or Schedule III of a classification system for controlled substances. The system categorizes controlled substances from Schedule I (drugs with a high potential for abuse and no accepted medical use) to Schedules II through V, in which each drug has a currently accepted medical use. (The ascending schedule numbers indicate a successively lower “potential for abuse” and “potential for psychic or physical dependence.” (21 United States Code Section 812; MCL 333.7210 through 333.7220).

There is wide variation in the requirements for use of opioid medications with some individual patients needing as much as 1,000 milligrams or more of morphine per hour to reduce pain to a level at which they can function. There is, however, widespread misperception regarding the maximum amount of opioids that can be safely administered and the likelihood of addiction in patients who take opioids. The relative use in Michigan of two of the most common drugs, morphine and codeine, suggests that a great deal of education is

required. The recent reduction in use of a third drug, meperidine, points out that Michigan professionals can react positively to education.

Codeine is an opioid that is used for mild to moderate pain (reported by patient as 1-5 on a 0-10 scale). It is a weak opioid when prescribed in the usual dosage. Codeine often is given in combination with non-opioid drugs that have serious adverse side effects, thus limiting the amount of codeine that can be prescribed.²⁴ Despite the disadvantages of codeine as an analgesic to relieve pain, and its limited usefulness in dealing with severe pain (described by patients as 6 and above on a 0-10 scale), codeine is widely prescribed by Michigan physicians. In 2000, Michigan ranked first in the nation in prescriptions of codeine, at 169 percent of the national average of grams per 100,000 population.²⁵ Michigan has ranked first to third in codeine use since 1990, the year following adoption of the Triplicate Prescription Program, the predecessor to the OPP.

Morphine, a Schedule II opioid, is the drug of choice in management of severe pain.^{2,8} It is the most widely used opioid for moderate to severe pain because of its availability in a wide variety of dosage forms, its well-characterized pharmacokinetics, and its relatively low cost.²

Table V(B)1: Ranking of Michigan among states in use of selected opioids.

	1988	1994	1999
Codeine _____	2*	3	1
Morphine _____	18	23	22
Meperidine _____	16	23	40

*1990 data; 1988 data unavailable.

Source: U.S. Department of Justice, Drug Enforcement Administration, Automation of Reports and Consolidated Orders System.

Since 1990, Michigan physicians have ranked only slightly above the national average in its use.²⁵

Meperidine (Demerol) is a Schedule II opioid that previously was widely used for pain management. In 1988, Michigan ranked 16th among the states in the use of meperidine.²⁵ In the early 1990s, federally sponsored guidelines for pain management^{2,8} recommended against meperidine use because of its serious side effects. Use of meperidine in the United States

subsequently dropped, and its use in Michigan dropped significantly. In 1999, Michigan ranked 40th in its use. These data suggest a positive response by Michigan health care professionals to the federal recommendations.

Michigan citizens, health professionals, and law enforcement personnel are concerned about the health effects of illicit drugs and medications diverted for inappropriate or illegal use. The best data about such health effects come from the Drug Abuse Warning Network (DAWN), a federal program that uses medical records to monitor national drug abuse trends and adverse health effects.¹⁶ DAWN also monitors adverse effects of appropriately prescribed medications.

Data on patients six years old and older are collected from non-federal short-stay general hospitals that have a 24-hour emergency department (ED). Using medical records, data on all patient visits related to problems with drug use are reported. These usually involve drug overdoses, but they also include results of long-term drug use and adverse reactions to drugs.

DAWN defines drug abuse as the non-medical use of a substance for psychotropic effect, dependency, or suicide attempt or gestures. Drug abuse can involve the use of illicit drugs,

prescription drugs used in a manner that is inconsistent with accepted medical practice, and over-the-counter drugs used in a manner contrary to approved labeling.

The following table shows DAWN “mentions” for Detroit (the only site for which there is data collection in Michigan) for the years 1988 (before the OPP), 1992, 1996, and 1999. Although Detroit data vary from national DAWN data in other respects, they are consistent with national DAWN data in the small percentage of drug abuse admissions related to opioids. For example, in 1999 ED admissions for drug abuse, 2.2 percent were for opioid analgesics, 23.8 percent were for alcohol in combination with other drugs, and 47.8 percent were for illicit drugs such as cocaine, heroin, and marijuana. Based on DAWN data, it appears that the diversion of Schedule II or Schedule III drugs contributes only minimally to the problem of substance abuse. The negative effects of drug use seem to be due to illicit drugs, alcohol, and other classes of prescription medications such as benzodiazepines, antidepressants, and antipsychotics. None of these medications are monitored by the OPP, and few have a role in the treatment of pain.

Table V(B)2: Percentages of substance abuse in Detroit listed by DAWN category

Year	Opioid analgesics	Non-opioid analgesic	Alcohol plus other drugs	Illicit drugs	Other drugs	Total number of mentions
1988	3.6	3.9	17.8	40.3	34.1	17,600
1992	3.1	5.5	25.8	36.4	29.2	28,378
1996	2.8	2.5	23.3	46.0	25.0	39,037
1999	2.2	1.7	23.8	47.8	24.5	30,263

Source: Drug Abuse Warning Network

The media have reported increasing use, abuse, and lawlessness associated with the drug OxyContin (long-acting oxycodone) in certain mid-Atlantic and Eastern states.^{26,27,28,29} The committee notes that there has been criticism of the manner in which this drug is formulated and of certain highly aggressive marketing practices of the manufacturer. The current form of the medication allows it to be crushed, thereby overcoming the time release feature and enabling rapid onset of action, which gives the drug more addiction potential. It is notable that other technology exists that makes it impossible to overcome the time-release feature, as is the case with the formulation of RitalinSR; i.e., it is not possible to accelerate the effect of RitalinSR by crushing it or chewing it because of the way in which the particles of the drug and its medium are bound. The New York Times reported that the manufacturer of OxyContin and the federal Drug Enforcement Administration are reviewing possible changes in manufacturing and marketing practices.²⁶

The committee did not find that there has been an increase in deaths in Southeast Michigan associated with OxyContin. Specifically, the Wayne County Medical Examiner’s Office said there has been no marked change recently in the incidence of OxyContin- or oxycodone-associated deaths among cases it has investigated.³⁰

Public hearing testimony and evidence collected by the committee indicate that, despite the availability of information about pain management, there is a serious lack of understanding among Michigan professionals of the principles of effective pain management. For example:

- There are widespread misperceptions about the efficacy and safety of opioid medications, which in fact are highly effective and essential therapies for the management of pain and are frequently the drug of choice.^{2,8,19}
- Some professionals and others think opioids are highly addictive and contribute to substance abuse.²¹ In fact, patients using opioids for pain management rarely become addicted, with the infrequent exception of people with a pre-existing addiction to drugs or alcohol.³¹ Some professionals and others don't understand the distinction between addiction and physical dependence, or the concept of tolerance to drugs.³²
- Some providers fear they will lose their licenses if they prescribe high dosages of opioids or prescribe them for more than a brief period of time.^{23,33,34} In fact, officials of the Michigan OPP, which tracks prescriptions of Schedule II drugs, do not initiate enforcement actions and only provide information to licensing boards and other regulators that have ongoing investigations for reasons unrelated to the OPP.³⁵
- Some physicians think Schedule II opioids should be used only as a last resort for so-called "intractable" pain when other pharmacological and nonpharmacological modalities have failed.³⁶ In fact, Schedule II opioids are frequently the initial drug of choice for pain management.^{2,8} A consensus policy statement issued in 2001 by the American Pain Society and the American Academy of Pain Medicine states that opioids are appropriate for the treatment of chronic nonmalignant pain when other treatments have not relieved the pain.^{37,6}
- Some physicians believe that, because prescriptions of Schedule II opioids are tracked through the OPP, they are less safe than Schedule III drugs, which are currently not tracked. In order to avoid scrutiny and minimize administrative burdens from the OPP,³⁴ some physicians prescribe Schedule III rather than Schedule II drugs, even when they know that Schedule II drugs are the drugs of choice.⁷ In fact, many Schedule III drugs are less safe because they are dispensed in combinations with drugs that pose serious risks of injury to major organs (e.g. liver, kidneys, and stomach) and potential adverse effects on the nervous system.^{3,5,6,38}
- Some physicians and other professionals do not understand the dosages of Schedule II opioids that may be safely administered; in fact, there is wide variation in opioid dosage requirements for individual patients.^{2,7,8}
- Physicians who are not specialists in pain management often question the recommendations of pain specialists and prescribe lower-than-optimal dosages; also, nurses sometimes question orders and may fail to administer or delay administering prescribed opioids.¹⁹
- Some physicians use placebos to test the veracity of patient complaints of pain. Placebo use in clinical pain management implies that the health professional does not believe or value a patient's subjective assessment of his or her own pain. In fact, there is currently no clinically appropriate or ethically sound role for the use of placebos in the treatment of pain.³

2 The Michigan Department of Consumer and Industry Services (MDCIS) should adopt licensing requirements for health facilities and agencies that promote service- and unit-specific education programs for all health professionals on effective pain and symptom management.

Rationale.

Public hearing testimony and the experiences of members of the committee are replete with anecdotal information about health professionals, including physicians and nurses, who are not familiar with the principles of pain management that are used in organized pain management services and who either do not prescribe consistently using those principles or who fear administering prescribed medications because of their lack of familiarity with those principles.^{2,8,19}

Professional education in pain and symptom management must promote assessment and treatment of pain at the bedside as it is occurring. This will improve outcomes by preventing future damage to these patients' nervous systems and will reduce the reportedly high proportion of patients and residents of health facilities who incur moderate to severe pain at the end of life and at other times.^{1,33}

3 In order to effect institutional change, MDCIS and MDCH should adopt by regulation and monitor the progress of licensed health facilities and agencies in implementing the requirements for treatment of pain of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) so that facilities demonstrate effective and acceptable assessment and treatment of pain for each patient in an individual and timely manner.

Rationale

The JCAHO currently accredits about 20,000 hospitals, nursing homes, and home care agencies across the country. Accredited inpatient facilities care for about 96 percent of the nation's patients.³⁹ The JCAHO requires that hospitals assess patients for pain, identify the level of pain, and provide effective and acceptable treatment of that pain on an individual and timely manner. These standards are also required by the Centers for Medicare and Medicaid Services (CMS) for hospitals that obtain certification through JCAHO "deemed status" (which indicates that they meet Medicare and Medicaid certification requirements).⁴⁰ In addition, Michigan requires licensed hospitals that are certified on the basis of deemed status (Michigan Administrative Code, R.325.1021) to follow the JCAHO accreditation standards. It is appropriate that adherence to these requirements be monitored and enforced by the MDCIS as a part of the licensing and re-licensing processes, and by MDCH in connection with the all pertinent aspects of the Medicaid program, including enrollment, contracting, quality assurance and reimbursement.

The committee also recommends that the MDCH and MDCIS require licensed nursing care facilities to meet these standards; that the MDCIS continue to certify nursing facilities for Medicare participation; and that MDCIS incorporate these requirements in the Michigan Administrative Code as part of licensing requirements for all hospitals (whether or not certified or accredited) and all nursing facilities, as well as other licensed health facilities and agencies.

4 All applicable health profession licensing boards should adopt and disseminate the "Model Guidelines for the Use of Controlled Substances for the Treatment of Pain," promulgated by the Federation of State Medical Boards, and adopt policy declaring that undertreatment and inappropriate treatment of pain will be scrutinized.

Rationale

Adoption of these guidelines would improve the quality of pain management for all Michigan citizens and would protect Michigan physicians from administrative and criminal sanctions when they follow the guidelines. These guidelines enhance effective pain management in a changing clinical environment. Adoption of the guidelines would help physicians overcome their fear of regulatory scrutiny and would protect them from inappropriate administrative and criminal prosecution when they prescribe opioids in the manner described in the guidelines.^{41,42} These guidelines would be an educational tool and a resource for physicians who have questions about the efficacy of, indications for, and protocols for prescribing Schedule II drugs.⁴²

As of April 17, 2001, 10 of the 69 medical boards across the country had adopted these guidelines as written; 38 others adopted language that is to some extent consistent with the guidelines, but with wide variation among them. Michigan statutory language is generally consistent with the guidelines, in that it provides for balance between adequate pain control and prevention of drug diversion. It is notable, however, that the guidelines also suggest, in part, that opioids should be reserved only for terminal illness or intractable pain^{41,43} (see rationale to Recommendation 6 and Appendix 3 to this chapter).

Although the health profession licensing boards from around the nation have in the past disciplined physicians for over-prescribing controlled substances for pain management, there are also recent examples of disciplinary actions for undertreatment. In one such case, the Oregon Board of Medical Examiners disciplined a physician in 1999 for failure to prescribe adequate pain medication for patients, including some terminally ill patients.⁴⁴ The offenses included prescribing Tylenol to treat musculoskeletal pain; prescribing paralytic agents but no sedatives or analgesics, for an intubated, mechanically ventilated woman who was agitated and restless; and using physical restraints, but no anxiolytics (minor tranquilizers) or sedatives or analgesics, to intubate a patient who had severe pneumonia associated with hypoxemia.

Commenting on this case, James R. Winn, MD, executive vice president of the Federation of State Medical Boards, said: “Any doctor who is practicing this type of medicine can expect to get into trouble if it comes to the attention of the board. Whether they failed to provide appropriate pain relief or failed to provide appropriate antibiotic therapy ... if they fall below the standard of care, then they are subject to being disciplined. ... What is unusual about this case is there are groups of doctors advocating that doctors be disciplined when they fail to provide adequate pain relief.”⁴¹

5 The Legislature should add a subsection to the Policy on Patient and Resident Rights and Responsibilities within the Public Health Code (MCL 333.20201(2)), stating that all patients have the right to adequate pain and symptom management and must be informed of that right. This section also should refer to the rights to palliative and hospice care.

Rationale

Many patients and their loved ones reported in public hearing testimony that for long periods of time they were not aware that their pain management was inadequate and that they simply thought it was normal and appropriate for the patient to be in pain.¹⁹ In the previously cited

study by Jacox and colleagues, patients with high pain levels and high satisfaction with their service were satisfied if they were asked about their pain by caregivers and if they did not have to wait long for treatment for their pain, regardless of the treatment's effectiveness.²¹ Some patients and families reported that only when their care was transferred to professionals with greater expertise in pain management did they realize that their prior pain management had been inadequate. This realization usually occurred when patients were transferred to facilities or units within facilities with pain management programs that functioned well or when they enrolled in a hospice program.

Patients and their families have a right to know that pain almost always can be managed effectively with readily available pharmacological and non-pharmacological interventions.^{2,8,45}

6 The Legislature should amend the Michigan Dignified Death Act (MDDA — MCL 333.5651 *et seq.*) to eliminate the terminology “life expectancy of less than six months” and replace it with language to require physicians who identify a patient with limited life expectancy due to advanced illness to provide the patient with information about options for management of pain and symptoms. Such information should be provided regardless of whether the patient continues on a course of curative medical care or combines this with or chooses palliative care or hospice care. MDCH and MDCIS should take a leadership role in disseminating information about the MDDA to professionals and the public because it is little known among physicians and is largely disregarded by them.

Rationale.

There have been inadequate efforts to educate and inform physicians of the responsibilities imposed by the MDDA, and there is little or no enforcement of the MDDA in its current form. The physician members of the committee are aware that many physicians do not know anything about the MDDA and others disagree with certain of its elements. It is consistent with legal and ethical standards that patients be informed of treatment choices, including the right to reject treatment. To that extent, the MDDA has positive aspects.

In its current form, the MDDA has two major flaws. First, it assumes that physicians can predict with certainty when a patient is going to die. It is very difficult for a physician to know when a patient has six months or less to live. Life expectancy is more predictable with some types of cancer, but many other conditions, such as congestive heart failure, could be fatal in any acute episode, and yet many patients survive numerous individual episodes and live for years. Respondents at the Commission's public hearings reported that some cancer patients who have good pain control also improve enough to be released from hospice care.¹⁹

The MDDA should be amended to eliminate the risk of liability and to make it a part of the allopathic and osteopathic medicine portions of Article 15, the occupations part of the Michigan Public Health Code (MCL 333.16101 *et seq.*).

The second flaw of the MDDA is that it requires physicians to inform patients or their surrogates that they “may choose palliative care and treatment including, but not limited to, hospice care and pain management” [MCL 333.5655 (b)]. This language suggests that patients who choose the recommended medical treatment have not necessarily made

informed choices for pain and symptom management. It also creates a misconception that patients must endure pain if they continue with curative medical and surgical care and services and do not choose palliative care. This language should be changed to emphasize that patients have a right to information about pain and symptom management regardless of whether they have a life-limiting condition and whether they choose palliative care.

- 7 The Legislature should amend all statutes to eliminate the use of the term “intractable pain” or, amend to change it to “pain.”

Rationale.

National authorities who have studied Michigan statutes find many elements that are currently in the statutory language that enhance pain management¹⁷ — and others that detract from good pain management. It is fortunate that Michigan did not follow other states in adopting an Intractable Pain Treatment Act, although some current Michigan statutes use the term “intractable pain.” Study groups⁴⁶ have identified that use of the term “intractable pain” in statutes puts undue restrictions on medical decision-making and patient access to pain therapies by:

- Defining medical use of opioids as a “therapy of last resort”
- Implying that opioids can be used for pain, only in cases in which the cause of pain cannot be removed
- Requiring evaluation of patients by a second physician
- Excluding pain patients with a history of drug abuse.

These same national authorities find the following elements in Michigan statutes that enhance good pain management:

- The Michigan Dignified Death Act (MDDA) (MCL 333.5655 and 333.5657). These sections entitle a terminally ill patient to be informed of the right to appoint a patient advocate; entitle the patient or surrogate to make an informed decision about whether to receive, continue, discontinue, or refuse medical treatment; entitle the patient or surrogate to information about palliative care, including pain management; and confer immunity from civil or criminal liability on physicians who orally and in writing provide such information and also obtain the signature of the patient or surrogate confirming receipt of a summary of the information.
- The MDDA (MCL 333.5658). This section permits a physician, as part of implementing a medical treatment plan for a terminally ill patient, to prescribe a controlled substance in good faith to alleviate pain; and it confers immunity from civil and criminal liability, as long as the prescription is for a legitimate and professionally recognized therapeutic purpose within the physician’s scope of practice and the physician holds a controlled substance license.
- The Michigan Public Health Code (MCL 333.16204c), that declares the legislative intent to be: 1) that “controlled substances” are appropriate in the medical treatment of certain forms of intractable pain, and 2) that efforts to control diversion or improper administration of controlled substances should not interfere with their legitimate, medically recognized use to relieve pain and suffering. This section reflects the concept of balance between effective pain management and efforts to control drug diversion. (See note below, however, about negative implications and erroneous use of term “intractable.”)

These same authorities identify the following Michigan statutory language that has a negative impact on effective pain and symptom management:

- The Michigan Public Health Code [333.16204a(7)], that defines the term “intractable pain.” This section suggests that opioids are not a legitimate part of professional practice and may be used only as a last resort, when no relief is possible or none has been found after reasonable efforts; and it interferes with medical decision making by requiring consultations in circumstances not required by standards of medical practice.
- The Michigan Public Health Code (MCL 16204c). The term “intractable” in this section creates an erroneous, clinically inappropriate, and negative implication that opioids should be used only as a last resort or where no relief is possible from other measures.
- The Michigan Controlled Substances Act (MCL 333.7333 and 333.7334). These sections require prescribers to use a special prescription form for Schedule II drugs, and many are opioid medications; impose a five-day limit for filling such prescriptions; and suggest erroneously that Schedule II drugs are more dangerous or less effective than other drugs.
- The Criminal Code (MCL 752.1027), contains a now-expired prohibition on assisted suicide. This section created an exception for “prescribing, dispensing, or administering medications or procedures if the intent is to relieve pain or discomfort and not to cause death, even if the medication or procedure may hasten or increase the risk of death” and thereby perpetuates the myth that opioids hasten death.

In addition, two statutes govern covered benefits of, respectively, commercial health insurance companies (MCL 500.2212a) and health care corporations such as Blue Cross and Blue Shield (MCL 550.1402a). Each statute requires that the certificate describe benefits for evaluating and treating “intractable pain.” That phrase should be changed to “pain.”

8 The Legislature should repeal the Official Prescription Program (OPP) because in its current form the OPP impairs access to effective pain management without providing a corresponding benefit in the control of prescription drug diversion or quality of pain management.

Rationale.

The committee has determined that the OPP (found at MCL 333.7333 and 333.7334) deters some physicians from prescribing Schedule II opioid medications. Physicians may fear regulatory scrutiny, which results in a “chilling effect” on their willingness to prescribe Schedule II opioids and deprives patients of the type of pain and symptom management they need. The requirement that prescribers use a special prescription form is a deterrent to good care because of perceived security efforts to protect the special prescription forms, and the fact that the prescriptions are numbered and must be accounted for. As a practical matter, the forms often are not available when necessary. Many physicians do not even participate in the OPP, and some who do participate rarely prescribe. Other physicians who say that they use the OPP without adverse personal consequences also say that they cannot convince their peer physicians who do not use the OPP that they can use the OPP without fear of regulatory consequences.⁴⁷

The facts are that:

- 45 percent (3,439) of Michigan's licensed dentists have OPP privileges.
- 53 percent (16,952) of Michigan's licensed allopathic physicians (MDs) have OPP privileges.
- 54 percent (3,355) of Michigan's licensed osteopathic physicians and surgeons (DOs) have OPP privileges.
- Of the MDs and DOs above (20,307 total), 1,292 prescribers issue more than 20 prescriptions each month for amphetamines. This leaves 19,015 (93.6 percent of the total OPP prescribers) who primarily prescribe opioids.³⁵

OPP personnel at the Department of Consumer and Industry Services (DCIS) report that:

- OPP data are not used as a primary investigative tool by the health profession licensing boards.
- The OPP staff does not report individual prescribing patterns or otherwise make complaints to the health care licensing boards.
- The OPP staff only respond to requests for information from field investigators after an investigation of a prescriber has begun, not those initiated by the OPP staff or based on OPP data.

Physicians who believe they are among the highest-volume OPP prescribers advise that they have had no inquiry from the OPP staff or other obvious scrutiny as a result. OPP administrators say that none of the top 100 prescribers has been the subject of disciplinary action for prescription of opioids.⁴⁷ These top 100 OPP prescribers include six dentists (five oral surgeons and one endodontist) and 94 physicians (75 MDs and 19 DOs). Of these 94 physician prescribers, 27.6 percent are from specialties that might primarily prescribe amphetamines (pediatrics, child psychiatry, and psychiatry) and 60.6 percent are from specialties that more routinely might prescribe opioids (anesthesia, oncology, family practice, internal medicine, general practice). The top 100 prescribers write on average between 30 and 400 prescriptions each per month.

The committee has determined that the OPP has not had a sufficiently measurable effect on prevention of drug diversion to justify the adverse effect it has on patients' ability to obtain effective pain and symptom management. Also, it appears that any current problem of diversion is focused on Schedule III drugs, which are not tracked, not on Schedule II opioids. Furthermore, the available data do not indicate that adoption of the OPP has had any effect on diversion of Schedule II drugs.⁴⁸

Despite diligent inquiry, the committee was not able to obtain statistically valid information about pre-OPP drug diversion from the State of Michigan (including the State Police), the federal Drug Enforcement Administration (DEA), or the Detroit Police Department. The committee was able to obtain only a small amount of information from the State Police about arrests for diversion of Schedule II drugs since the development of the OPP, and no information about diversion of Schedule III drugs, which are not tracked by the current system.⁴⁹ It is not assumed that law enforcement personnel were unwilling to provide the information they have, but rather that they do not track cases in the manner requested.⁵⁰ All sources repeatedly stated that they would be able to give case-specific information on request.

A research assistant then assigned to the Commission requested information from the Michigan State Police in August 2000, including arrest and conviction records for diversion of Schedule II and Schedule III drugs. Initially, the committee was informed that no information was available.⁴⁴ Subsequently, through the Governor's Office, the committee was informed that there were 20 to 30 arrests for drug diversion by the State Police in each of 1998 and 1999, but that it was possible that more information could be received from inquiries of the police in some of the state's larger cities.

A Freedom of Information Act (FOIA) request was sent to the Detroit Police Department in October 2000, requesting information about arrests and convictions for diversion of controlled substances in 1998 and 1999, as well as 1988, if available. In December, the department responded by letter from the Police Legal Advisor Section that it does not maintain such records. After follow-up discussions with an attorney in that section,⁵¹ the committee received a telephone communication that advised that the Detroit Police Department ordinarily refers such cases to the State Police or the Michigan Attorney General.⁵²

Also in October 2000, the committee filed a FOIA request with the DEA seeking information on arrests and convictions for drug diversion. The DEA subsequently replied by letter that it does not keep information in the form requested. The committee had been advised by Marsha Jones, manager of the DEA Diversion Program, Detroit Region, to file the FOIA request. Subsequently, Jones advised that generally there are no compilations of arrests and convictions, but that individual agents and officials of the DEA are able to gain access to individual case information and investigation files when they are called upon to provide information or to testify.⁵⁰ That was confirmed in a letter dated March 12, 2001, from Katherine L. Myrick, chief of the DEA Freedom of Information Operations Unit.

OPP personnel say they have been told of past cases in which people sought many prescriptions from more than one prescriber. OPP personnel also have a definition of people called "doctor shoppers," but there are no data on the numbers of these people; nor is it possible to determine the degree to which these are people whose legitimate need for pain control was simply not met by their physicians.⁵³ The committee has communicated with health providers in California who have a system in place for identifying patients who obtain prescriptions from more than one prescriber and for directing them toward the clinically appropriate pain specialists or addiction therapists for treatment. They found that 60 percent of the patients referred to them (the potential doctor shoppers) had legitimate pain-relief needs and that the referrals represented only 3.5 percent of the patients receiving opioids in their health system.⁵⁴

Overall, the numbers of drug-related disciplinary actions against health care professionals have not changed significantly from the period before the OPP (1988 data) to the present (1999 data).

At the end of 1999, there were 146,616 nurses, 31,944 allopathic physicians, 6,439 osteopathic physicians, and 7,709 dentists licensed in Michigan.⁵⁵ All told, these 192,708 Michigan health care practitioners accounted for eight cases of prescription drug diversion.

Table V(B)3: Drug-related disciplinary actions against health care professionals in Michigan

	Total allegations	Disciplinary actions	Drug-related disc. actions	Actions for drug diversion
Board of Medicine				
1988	463	44	19	8
1999	540	127	17	3
Board of Osteopathic Medicine & Surgery				
1988	155	14	4	0
1999	153	27	6	1
Board of Nursing				
1988	191	71	40	11
1999	556	302	121	4
Board of Dentistry				
1988	167	7	3	1
1999	288	91	4	0
Board of Pharmacy				
1988	166	117	49	10
1999	204	160	34	12

Sources: 1999: Michigan Department of Consumer and Industry Services; 1988: Michigan Department of Licensing and Regulation (a predecessor agency)

In 1999, 11,466 pharmacists were licensed to practice in Michigan. In their dispensing role, there were 12 drug diversion cases, which is not significantly different from the 10 cases reported in 1988. This is a small number of cases not identified with current OPP data. Other means of identifying these cases and assisting law enforcement would be helpful.

9 The Legislature should replace the current OPP with a system that supports electronic monitoring; is balanced in its approach to high-quality pain management and its desire to limit prescription drug diversion; requires no additional special prescription form; is efficient and invisible to the patient and practitioner; and provides information that is well understood and available to all those who need it.

Rationale.

OPP data are currently not used for reporting purposes in the state, either for tracking drug diversion, or for assessing the effectiveness of pain management measures.⁵³ If the OPP were eliminated, the resources now invested in the program could be used to support an electronic monitoring program for both certain Schedule II opioids and Schedule III opioids or other drugs combined with opioids classified under Schedule III.

A new system using the resources currently allocated to the OPP on an annual basis should replace the one in current use. There is evidence that just changing to an electronic monitor could be cost-neutral or result in savings. The current system in Michigan costs approximately \$780,000 a year to administer. Officials of the Kentucky system discussed

below, estimate annual costs for their program at less than \$1,000,000⁵⁶ (see Appendix 2 to this chapter) and also identify significant savings for law enforcement. These figures are significantly higher than those from a recently released federal study of state prescription-monitoring programs that estimates an electronic monitoring system in a state with a population the size of Michigan's would cost between \$100,000 and \$138,000 a year.⁵⁷

The committee did not undertake a systematic review of other available monitoring systems across the country, and is not in a position to recommend any particular system, but committee members learned from the DEA's Marsha Jones that the Kentucky All-Schedule Prescription Electronic Reporting system (KASPER) electronically tracks all schedules from Schedule II through Schedule V.⁵⁶ According to Kentucky authorities, including Danna Droz, director of the Drug Control Branch of the Division of Adult and Child Health of the Kentucky Department of Public Health, KASPER became effective January 1, 1999, and has had widespread acceptance after initial start-up issues were resolved. The vast majority of Kentucky pharmacies (more than 99 percent, according to a staff person) are online with the system; pharmacies, physician dispensers, and veterinarians that are not online report monthly on paper forms.⁵⁶

Michigan's new data collection system should be developed in consultation with pain management experts and should meet the following goals:

- Monitor the instances of actual and suspected drug diversion and abuse of the included opioids
- Organize the data collection effort to permit study of pain and symptom management on a drug-by-drug basis, use of these agents in individuals with limited life expectancy due to severe advanced illness, and instances of medical complications
- Provide information about the relative use of Schedule II and Schedule III opioids per 100,000 population in Michigan and compare with states that do and do not have controlled substances tracking programs with the nation as a whole
- Provide information in an effective format to physicians about their prescribing practices and about use by their patients
- Provide information about the monitoring program to physicians in order to alleviate fears of regulatory scrutiny
- Provide for annual reporting both for tracking drug diversion and as a factor in determining quality of care
- Be cost-neutral or produce savings compared to the present system.

The committee has also learned that some pharmacists find the OPP helpful in resolving questions about the legitimacy of Schedule II prescriptions and in fulfilling reporting requirements to the Board of Pharmacy.⁵⁸ The committee notes that these same pharmacists face similar issues about the legitimacy of Schedule III prescriptions and have a regulatory duty to verify the legitimacy of these prescriptions as well. These concerns could be alleviated by an electronic tracking system of both Schedule II and Schedule III opioids. Pharmacists currently do not fill prescriptions that they find questionable. It may be useful to require pharmacies to report to the Board of Pharmacy all prescriptions for Schedule II or Schedule III opioids that they do not fill for any reason, other than that they do not stock the applicable drug. Reasons for not filling would include:

- Inadequate supply
- Suspicions that the prescription may not be valid
- Suspicions that a patient is seeking prescriptions simultaneously from more than one prescriber for other than legitimate pain control purposes.

The committee respects the pharmacists' concerns but believes they are outweighed by the need for access to effective pain management and can be alleviated by means that do not have a deleterious effect on the quality of patient care. One such means is electronic monitoring of at least Schedule II and Schedule III medications.

The committee also learned that there are a few physicians who doubt the safety and efficacy of all Schedule II opioids and see the OPP as a reason not to have to prescribe them.⁵⁹ These physicians should either be educated as to the effective use of Schedule II opioids (as well as other pharmacological and non-pharmacological modalities) in pain management or should be willing and encouraged to refer their patients who have pain management needs.

10 The Legislature, MDCH, and MDCIS should work to minimize state regulatory impediments to effective pain medications and should work with the Michigan Congressional delegation and federal officials to minimize federal regulatory impediments concerning prescriptions, including the time limits for filling them, prohibitions on refills, telephone orders, and electronic transfer of prescriptions.

Specific changes should include:

- Lengthening the time limit for filling prescriptions from five days to six months (state).
- Lengthening the period from 72 hours to 14 days for completely filling a prescription that is only partially filled (state).
- Permitting up to five refills of prescriptions over a six-month period (federal and state).
- Eliminating restrictions on telephone orders (federal and state).
- Eliminating the prohibition on electronic transfer of prescriptions of Schedule II medications (federal and state).

Rationale.

The committee has determined that some aspects of the Michigan controlled substances laws impair the ability of patients to obtain effective pain and symptom management. These issues include:

- A requirement that Schedule II prescriptions be dispensed within five days of the date they are written (MCL 333.7333(2)). This requirement was cited by physicians who responded to the committee's survey (see Appendix 1 to this chapter) as one facet of the OPP that impedes effective pain management by making it difficult for patients with chronic pain, who are not mobile and lack adequate support from family or others, to have their prescriptions filled in a timely manner. The Advisory Committee on Controlled Substances has recommended extending this period from five days to 90 days. This committee sees no reason why the time period could not be further increased to 180 days.
- Allowing only 72 hours to complete filling a prescription when the pharmacy has only a partial supply (Michigan Administrative Code, R. 338.3166). In general, a prescription must either be completely filled or rewritten for the remainder, which often requires

another trip to the physician for an additional prescription and an additional co-pay. There is some relief for dispensing partial prescriptions when the pharmacy does not have adequate supplies and can fill the remainder within 72 hours, and for dispensing partial prescriptions for terminally ill people who may not be able to use a full prescription. The regulations should be changed to lengthen this period to at least 14 days. If a pharmacy does not have an adequate supply and has not previously placed an order, the supply will not usually arrive in 72 hours, especially if a weekend is involved.

- The prohibition on refills of Schedule II opioids (Controlled Substances Act: 21 United States Code, Section 829; MCL 333.7333 (2) and Michigan Administrative Code R. 338.3168). These provisions, and the fact that many third party prescription payors pay only for a 30-day supply, means that a patient with chronic pain must obtain new prescriptions and potentially incur the cost of otherwise unnecessary physician visits at least every 30 days. Such restrictions are not placed on medications for other chronic conditions such as anti-hypertensives for the treatment of hypertension, or insulin for the treatment of diabetes.
- A prohibition on electronic transmission of prescriptions for Schedule II opioids and limitations on telephone ordering. Under both state and federal law [Controlled Substances Act: 21 United States Code, Section 829; and MCL 333.7333(2) and 333.7334(6)], prescriptions must be written; telephone orders are permitted only in emergencies. This often subjects a patient with pain to unnecessary physician visits or at least visits to physician offices, if the mail cannot produce timely delivery to the patient or a representative so that the prescription can be dispensed within five days of the date it is written. It is not clear to this committee why prescriptions for Schedule III drugs can be transmitted electronically if the pharmacist verifies the authenticity of the transmission, but not prescriptions for Schedule II drugs. This is especially puzzling since the potential for abuse and diversion also exists with Schedule III drugs, which are often not as effective as Schedule II drugs and often have serious side effects.^{2,5,6,8}

11 MDCIS should develop a system and promulgate rules that require pharmacies to help patients find adequate supplies of pain medications when the pharmacy is unable to fill a valid prescription as presented.

Rationale.

The committee determined that pharmacies often do not have adequate supplies of Schedule II opioids and that some patients have trouble getting their prescriptions filled. For example, fewer than one-third of hospice directors estimate that adequate numbers of pharmacies in the areas they serve regularly stock Schedule II drugs. This has led more than three-quarters of the reporting hospices to execute contracts with local pharmacies to assure availability of Schedule II drugs for their patients.⁵³

Other patients requiring Schedule II drugs do not have the benefit of such contracts. Hospice directors also estimate that more than one-third of admitted patients are in a state of severe or uncontrolled pain.⁶⁰

In addition, there are reported instances of shortages of Schedule II opioids, particularly at year end, because of DEA limitations on the quantity of Schedule II opioids that can be manufactured for use in Michigan.⁶¹

The Committee suggests several strategies to implement this recommendation. The Board of Pharmacy should monitor availability of adequate supplies of all opioid medications in each region of the state and encourage the Attorney General of the United States to establish production quotas under 21 United States Code, Section 826 that take into consideration the quantity of Schedule II drugs required by Michigan citizens for the effective control of pain and symptom management. MDCIS and the Board of Pharmacy should make annual reports to the Governor and Legislature regarding distribution and utilization of Schedule II medications.

12 MDCH and the MDCIS Office of Financial and Insurance Services should encourage health plans and payors to minimize copays, deductibles and other restrictions on reimbursement for opioids prescribed for pain and symptom management.

Rationale.

Patients and families should not have to choose between pain management and financial well-being. If a patient is on a regimen of several controlled substances to provide optimal pain control, the patient will pay as many co-pays as there are drugs involved in the regimen. The committee recommends that only one co-pay be required for all the controlled substances so a patient with limited financial resources will not have to forgo optimal pain management.

There are many non-pharmacological treatments for pain and suffering. These include massage, therapeutic touch, aromatherapy, exercise and physical therapies, art and music therapy, pet therapy, psychosocial consultation, and spiritual consultation. This committee recommends that those who provide these therapies be compensated and that demonstration projects be funded to study how non-pharmacological treatments may be used to reduce the level of pain and suffering and to reduce the quantity (and cost) of controlled substances required to manage pain.^{40,62}

13 The MDCH, MDCIS, and the Department of Environmental Quality should explore ways to improve disposition of pharmaceuticals when no longer required for home use, such as by requiring that in settings that have a central point of control such as a nursing facility, hospital, or hospice program, unused pharmaceuticals be retrieved and redistributed to other patients with legitimate prescriptions. This will limit waste of medical resources and reduce costs. The Department of Environmental Quality should advise on the effects of pharmaceutical waste on the environment and methods to minimize any detrimental effect.

Rationale.

Current regulations require hospice personnel to waste unused portions of opioid medications that remain in the home of a patient after death. This must be witnessed and attested to by another licensed individual. Often large quantities of expensive medications are simply flushed into the Michigan water supply. The effect on the environment is not clear. In addition, families have often paid large amounts of money for these unused medications. These are precious medical resources. New ways of packaging, accounting for, distributing,

and redistributing medications and other medical supplies in the home setting need to be developed to limit waste.²⁰

Methodology.

The Committee on Pain and Symptom Management undertook the following tasks:

- Analysis of testimony given at five public hearings across Michigan in September 2000 and other submitted written testimony as it relates to comments on adequacy of pain and symptom management.
- Analysis of use of Schedule II and Schedule III opioids in Michigan and other states for periods before and since institution of the OPP, using 1988 and 1999 data from the DEA and the Automation of Reports and Consolidated Orders System.
- Analysis of federal DAWN data. The utility of these data was impaired by the fact that heroin and cocaine are recorded in the same category as morphine. Additional analysis was required. The Pain & Policy Studies Group, World Health Organization Collaborating Center for Policy and Communications, University of Wisconsin Comprehensive Cancer Center, Madison, under the direction of David Joranson, provided valuable analysis of Michigan- and opioid-specific data.
- Surveying Michigan physicians about (a) their experience with the OPP if they use it; or (b) their reasons for not using the OPP. This was undertaken in cooperation with the Michigan State Medical Society and the Michigan Osteopathic Association.
- Requesting information from the Michigan State Police, the DEA, and the Detroit Police Department about arrests and convictions for Schedule II and Schedule III drug diversion.
- Analysis of current top 100 OPP prescribers by specialty and number of prescriptions written monthly and type of medication by class prescribed.
- Evaluation of disciplinary actions of Michigan health providers associated with prescription drug diversion.
- Participation with the Controlled Substances Advisory Commission in an educational session presented by Stephanie Crawford, PhD, RPh, of the University of Illinois, whose research focuses on prescribing practices under the prescription drug monitoring programs in Michigan and Illinois.
- Evaluation of medical consequences of diverted prescription drugs using DAWN data for Michigan and the nation.
- Evaluation of Michigan statutes and regulations for language that enhances pain management or that impedes good pain care. This process included assistance from the Pain & Policy Studies Group and its comprehensive analyses.
- Evaluation of other systems for data collection regarding pain management and drug diversion, especially those from Kentucky, California, Illinois, and Nevada.

Membership:

The committee's members are drawn from the Commission and from the Advisory Committee on Pain and Symptom Management. They are: J. Kay Felt, JD, Chair, and Karen S. Ogle, MD, who serve on both groups; Commission members Thomas George, MD, Mary Anne Gorman, MSW, ACSW, Kim K. Kuebler, MN, RN, ANP-CS, and Jeanne G. Lewandowski, MD; and Advisory Committee members Ada Jacox, RN, PhD, and Valerie Kinsora.

Support was also provided by the following individuals, to whom the committee is most grateful:

Rosalie Baran, RPh, BS, MA, pharmacy specialist, drug control administrator, Michigan Department of Consumer and Industry Services, and secretary, Michigan Controlled Substances Advisory Commission.

Danna Droz, RPh, JD, manager, Drug Enforcement and Professional Practices Branch, Kentucky Department for Public Health, Frankfort.

David E. Joranson, senior scientist, director, Pain & Policy Studies Group, World Health Organization Collaborating Center for Policy and Communications, University of Wisconsin Comprehensive Cancer Center, Madison.

Stephanie Y. Crawford, PhD, associate professor and director of graduate studies, Department of Pharmacy Administration, University of Illinois at Chicago.

Thomas Lindsay, II, director, Bureau of Health Services, Michigan Department of Consumer and Industry Services.

Marsha R. Jones, manager, Diversion Program, Detroit Division, Drug Enforcement Administration, U.S. Department of Justice.

Sue Peine, program analyst, Liaison Unit, Liaison and Policy Section, Office of Diversion Control, Drug Enforcement Administration Headquarters, U.S. Department of Justice, Washington, D.C.

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Appendix 1. Description and results of survey of Michigan physicians.

End-of-life care for Michigan citizens often requires the use of medications that are regulated by Michigan's Official Prescription Program. Since evidence suggests that the OPP influences physician prescribing behavior, the committee undertook to survey practicing physicians in Michigan in order better to understand what impact the OPP has on their practice. (The survey instrument appears in Appendix D of this report.)

Methods. Surveys were distributed by conventional mail and electronically to members of the two major physician professional organizations in Michigan, the Michigan State Medical Society (MSMS) and the Michigan Osteopathic Association (MOA). Those who were sent the survey by conventional mail received a cover letter describing its purpose, the survey instrument, and a stamped return envelope. The survey, which was approved by the Michigan State University Committee on Research in Human Subjects, was conducted and data collected from November 2000 through January 2001.

The survey was designed to capture the following data:

- Physician prescriber demographics
- Degree of utilization of the OPP by physician prescribers
- For those not using the OPP, reasons why they don't
- Types of patients for whom respondents prescribe Schedule II medications
- Frequency and type of problems associated with prescribing Schedule II medications
- OPP effects on physician practice.

The survey was pilot-tested on experts in end-of-life care and on MSMS and MOA members who participated in an end-of-life training course in October 2000. Data analysis consisted of tabulating answers and grouping narrative responses by theme.

Respondents. Of the 413 responses, the largest proportion came from physicians with specialties in family practice (35.6 percent) and internal medicine (16.7 percent). Additional areas of expertise reported were geriatrics (5.8 percent), pain management (2.2 percent), and hematology/oncology (1.2 percent). Most (78.4 percent) were male, most (88.6 percent) identified themselves as practicing in an office or clinical outpatient setting, and most (79.4 percent) practiced in urban or suburban settings. Of the rural responders, one-third practiced in Michigan's Upper Peninsula.

Results. More than three-fourths (75.8 percent) of the respondents use the OPP in their practice; of those who do not, 41 percent were not familiar with it. Among those who do not use the OPP:

- 36 percent said they do not know how to obtain OPP prescriptions.
- 44 percent did not like to use a second prescription form.
- 32 percent said OPP prescriptions are not needed in their practice.
- 23 percent are concerned about caring for "doctor shoppers."
- 15 percent said the OPP makes the responders' cost to practice prohibitively high.
- 15 percent said they don't want to include patients who need Schedule II medications in their practice.

- 4 percent indicated they felt they are not qualified to care for patients requiring these medications.

Of the respondents who use the OPP, at least 74 percent said they prescribe these medications with equal frequency for the terminally ill, for chronic malignant pain, for chronic non-malignant pain, and for acute pain. More than one-fourth (26.2 percent) said they had no problems with the OPP prescriptions they write. Most of those who do have problems with OPP prescriptions connect the problems with pharmacies. Specifically:

- 68 percent say pharmacists are reluctant to fill emergency orders by phone.
- 50 percent say pharmacists are unwilling to provide more than a 30-day supply.
- 48 percent say their patients have difficulty finding pharmacies that stock adequate supplies of the prescribed medications.
- 39 percent say pharmacists question the prescriptions.
- 24 percent say pharmacists do not want to fill their prescriptions for Schedule II narcotics.

Almost two-thirds (61.2 percent) of the respondents said the OPP forms have no effect on their practice. Virtually the same proportion (60.3 percent) said they do not worry about regulatory scrutiny for their Schedule II prescribing.

Respondents' suggestions ranged from eliminating the program, to allowing refills, to changing the age identifier to date of birth, to methods of archiving data.

Discussion. The rate of response to the survey was lower than hoped for, and in retrospect it is clear that the committee's attempts to partner with the Michigan physician professional organizations was both worthwhile and problematic for data acquisition.

The organizations agreed to sponsor the study and to defray the cost of mailing. They distributed the survey instrument in the most cost-efficient manner: by including it and a cover letter in the midst of a monthly newsletter sent to all members, without any reference to it on the front of the publication. The respondents had to chance upon the survey, then be interested enough and willing to respond to it, without compensation. Clearly these events are relevant in data bias.

In January 2001, the survey was e-mailed to on-line members of MSMS and MOA in an effort to improve the data set, though less than a third of the membership is accessible online. The online survey may have resulted in some duplicate data, though responses from those identifying themselves as repeat responders were not included in the data analysis.

The respondents were all self-reporting, and they may not reflect accurately the scope of practice or prescribing of Schedule II medications in Michigan.

Conclusions. Data bias aside, the committee's survey of Michigan physicians survey produced significant information about the current state of Schedule II prescribing in the state. The effect the OPP has had on prescribing is identified, and the challenges the current system imposes on patient care and physician practice and concern are apparent in the responses. Opportunities exist to improve the monitoring program so that it is more responsive to physician concerns regarding the OPP and to remove real and perceived barriers to improved and effective pain management in Michigan.

Appendix 2. The Kentucky reporting system.

The following report is based on conversations with Danna Droz, manager of the Drug Enforcement and Professional Practices Branch of the Division of Adult and Child Health of the Kentucky Department of Public Health, which operates the Kentucky All-Schedule Prescription Electronic Reporting system.

The Kentucky All-Schedule Prescription Electronic Reporting system (KASPER) became effective Jan. 1, 1999. It requires pharmacies and other dispensers to make electronic or paper-copy reports of the dispensation of all controlled substances, including identifying information about prescribers, patients, the specific drug and quantity dispensed. It covers Schedules II through V medications. (Those who developed KASPER said they would never have developed a system for only Schedule II drugs since they knew that the greatest abuse in their state was of Schedule III and Schedule IV drugs. Another reason they included all schedules was that they thought it would be hard to make changes after the system was in operation.)

Physicians who provide more than a 48-hour supply of controlled substances, home health agencies, veterinarians, and other providers who dispense directly to the patient are also covered in this program. Out-of-state pharmacies are required to report drugs shipped into the state, but Kentucky does not receive reports from out-of-state pharmacies that serve patients who travel in person to the other state to have their prescriptions filled.

KASPER is online, as are 99 percent of the state's pharmacies. Pharmacies that are not online and the other types of dispensers report monthly on paper.

Reaction. There has been little complaint from pharmacies. State officials say the biggest problem has been to work with the other dispensers, especially physicians, to bring them into compliance. The officials were surprised how often veterinarians use controlled substances.

The most serious problems for physicians had to do with a special prescription form that was adopted by companion legislation and became effective on the same date as KASPER. Physicians have had very little problem with the electronic reporting issue as it is relatively invisible to them and they find having access to the reports very helpful (see below).

Access. A variety of people and organizations, including physicians and law enforcement personnel, may request access to KASPER data, which includes aggregate data about patients, prescribers, and pharmacies. Requests must be made in writing each time access is sought, but they may be sent by fax. The staff log in the request and verify the requester's right of access. Then pharmacists do the research and prepare the reports. The staff send the reports out by fax. The most time-consuming task is verifying the identity of patients about whom reports are requested, mainly because patients are identified not by Social Security number but by a variety of identifiers. There are about 250 requests per day, of which about 85 percent come from physicians.

Usefulness. Droz says she thinks KASPER has been a good tool for physicians in patient care management and useful in identifying possible abusers. Also, law enforcement officials have found KASPER an effective and cost-saving tool. In the past when there was a need to

investigate a physician or a patient, investigators would have to go from pharmacy to pharmacy, which could take from a few days to several weeks and had little assurance of success. Now, enforcement officials make a data request to KASPER, have all the information compiled and presented quickly, and know exactly where to go to collect the original evidence.

Cost. Droz estimates that the annual cost of the system is less than \$1 million. Staffing (full-time equivalents of 2.2 pharmacists and 1.75 support personnel) could be reduced by use of Social Security numbers as patient identifiers. Also, in order to assess the real costs to the state, it would be necessary to evaluate the efficiencies gained in law enforcement.

Appendix 3. “Model Guidelines for the Use of Controlled Substances for the Treatment of Pain.”

The recommendations contained herein were adopted as policy by the House of Delegates of the Federation of State Medical Boards of the United States, Inc., in May 1998.

Section I: Preamble

The (name of board) recognizes that principles of quality medical practice dictate that the people of the State of (name of state) have access to appropriate and effective pain relief. The appropriate application of up-to-date knowledge and treatment modalities can serve to improve the quality of life for those patients who suffer from pain as well as reduce the morbidity and costs associated with untreated or inappropriately treated pain. The Board encourages physicians to view effective pain management as a part of quality medical practice for all patients with pain, acute or chronic, and it is especially important for patients who experience pain as a result of terminal illness. All physicians should become knowledgeable about effective methods of pain treatment as well as statutory requirements for prescribing controlled substances.

Inadequate pain control may result from physicians' lack of knowledge about pain management or an inadequate understanding of addiction. Fears of investigation or sanction by federal, state and local regulatory agencies may also result in inappropriate or inadequate treatment of chronic pain patients. Accordingly, these guidelines have been developed to clarify the Board's position on pain control, specifically as related to the use of controlled substances, to alleviate physician uncertainty and to encourage better pain management.

The Board recognizes that controlled substances, including opioid analgesics, may be essential in the treatment of acute pain due to trauma or surgery and chronic pain, whether due to cancer or non-cancer origins...The medical management of pain should be based on current knowledge and research and include the use of both pharmacological and non-pharmacological modalities. Pain should be assessed and treated promptly, and the quantity and frequency of doses should be adjusted according to the intensity and duration of the pain. Physicians should recognize that tolerance and physical dependence are normal consequences of sustained use of opioid analgesics and are not synonymous with addiction.

The (name of board) is obligated under the laws of the State of (name of state) to protect the public health and safety. The Board recognizes that inappropriate prescribing of controlled substances, including opioid analgesics, may lead to drug diversion and abuse by individuals who seek them for other than legitimate medical use. Physicians should be diligent in preventing the diversion of drugs for illegitimate purposes.

Physicians should not fear disciplinary action from the Board or other state regulatory or enforcement agency for prescribing, dispensing or administering controlled substances, including opioid analgesics, for a legitimate medical purpose and in the usual course of professional practice. The Board will consider prescribing, ordering, administering or dispensing controlled

substances for pain to be for a legitimate medical purpose if based on accepted scientific knowledge of the treatment of pain or if based on sound clinical grounds. All such prescribing must be based on clear documentation of unrelieved pain and in compliance with applicable state or federal law.

Each case of prescribing for pain will be evaluated on an individual basis. The board will not take disciplinary action against a physician for failing to adhere strictly to the provisions of these guidelines, if good cause is shown for such deviation. The physician's conduct will be evaluated to a great extent by the treatment outcome, taking into account whether the drug used is medically and/or pharmacologically recognized to be appropriate for the diagnosis, the patient's individual needs — including any improvement in functioning — and recognizing that some types of pain cannot be completely relieved.

The Board will judge the validity of prescribing based on the physician's treatment of the patient and on available documentation, rather than on the quantity and chronicity of prescribing. The goal is to control the patient's pain for its duration while effectively addressing other aspects of the patient's functioning, including physical, psychological, social and work-related factors. The following guidelines are not intended to define complete or best practice, but rather to communicate what the Board considers to be within the boundaries of professional practice.

Section II: Guidelines

The Board has adopted the following guidelines when evaluating the use of controlled substances for pain control:

1. Evaluation of the Patient

A complete medical history and physical examination must be conducted and documented in the medical record. The medical record should document the nature and intensity of the pain, current and past treatments for pain, underlying or coexisting diseases or conditions, the effect of the pain on physical and psychological function, and history of substance abuse. The medical record also should document the presence of one or more recognized medical indications for the use of a controlled substance.

2. Treatment Plan

The written treatment plan should state objectives that will be used to determine treatment success, such as pain relief and improved physical and psychosocial function, and should indicate if any further diagnostic evaluations or other treatments are planned. After treatment begins, the physician should adjust drug therapy to the individual medical needs of each patient. Other treatment modalities or a rehabilitation program may be necessary depending on the etiology of the pain and the extent to which the pain is associated with physical and psychosocial impairment.

3. Informed Consent and Agreement for Treatment

The physician should discuss the risks and benefits of the use of controlled substances with the patient, persons designated by the patient or with the patient's surrogate or guardian if the patient is incompetent. The patient should receive prescriptions from one physician and one pharmacy where possible. If the patient is determined to be at high risk for medication abuse or have a

history of substance abuse, the physician may employ the use of a written agreement between physician and patient outlining patient responsibilities, including

- urine/serum medication levels screening when requested
- number and frequency of all prescription refills
- reasons for which drug therapy may be discontinued (i.e., violation of agreement).

4. Periodic Review

At reasonable intervals based on the individual circumstances of the patient, the physician should review the course of treatment and any new information about the etiology of the pain.

Continuation or modification of therapy should depend on the physician's evaluation of progress toward stated treatment objectives, such as improvement in patient's pain intensity and improved physical and/or psychosocial function, i.e., ability to work, need of health care resources, activities of daily living and quality of social life. If treatment goals are not being achieved, despite medication adjustments, the physician should reevaluate the appropriateness of continued treatment. The physician should monitor patient compliance in medication usage and related treatment plans.

5. Consultation

The physician should be willing to refer the patient as necessary for additional evaluation and treatment in order to achieve treatment objectives. Special attention should be given to those pain patients who are at risk for misusing their medications and those whose living arrangement pose a risk for medication misuse or diversion. The management of pain in patients with a history of substance abuse or with a comorbid psychiatric disorder may require extra care, monitoring, documentation and consultation with or referral to an expert in the management of such patients.

6. Medical Records

The physician should keep accurate and complete records to include

- the medical history and physical examination
- diagnostic, therapeutic and laboratory results
- evaluations and consultations
- treatment objectives
- discussion of risks and benefits
- treatments
- medications (including date, type, dosage and quantity prescribed)
- instructions and agreements
- periodic reviews.

Records should remain current and be maintained in an accessible manner and readily available for review.

7. Compliance With Controlled Substances Laws and Regulations

To prescribe, dispense or administer controlled substances, the physician must be licensed in the state and comply with applicable federal and state regulations. Physicians are referred to *the Physicians Manual of the U.S. Drug Enforcement Administration* and (any relevant documents issued by the state medical board) for specific rules governing controlled substances as well as applicable state regulations.

Section III: Definitions

For the purposes of these guidelines, the following terms are defined as follows:

Acute Pain

Acute pain is the normal, predicted physiological response to an adverse chemical, thermal or mechanical stimulus and is associated with surgery, trauma and acute illness. It is generally time-limited and is responsive to opioid therapy, among other therapies.

Addiction

Addiction is a neurobehavioral syndrome with genetic and environmental influences that results in psychological dependence on the use of substances for their psychic effects and is characterized by compulsive use despite harm. Addiction may also be referred to by terms such as “drug dependence” and “psychological dependence.” Physical dependence and tolerance are normal physiological consequences of extended opioid therapy for pain and should not be considered addiction.

Analgesic Tolerance

Analgesic tolerance is the need to increase the dose of an opioid to achieve the same level of analgesia. Analgesic tolerance may or may not be evident during opioid treatment and does not equate with addiction.

Chronic Pain

A pain state which is persistent and in which the cause cannot be removed or otherwise treated. Chronic pain may be associated with a long-term incurable or intractable medical condition or disease.

Pain

An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.

Physical Dependence

Physical dependence on a controlled substance is a physiologic state of neuro-adaptation which is characterized by the emergence of a withdrawal syndrome if drug use is stopped or decreased abruptly, or if an antagonist is administered. Physical dependence is an expected result of opioid use. Physical dependence, by itself, does not equate with addiction.

Pseudoaddiction

Pattern of drug-seeking behavior of pain patients who are receiving inadequate pain management that can be mistaken for addiction.

Substance Abuse

Substance abuse is the use of any substance(s) for non-therapeutic purposes or use of medication for purposes other than those for which it is prescribed.

Tolerance

Tolerance is a physiologic state resulting from regular use of a drug in which an increased dosage is needed to produce the same effect, or a reduced effect is observed with a constant dose.

V(C). Reimbursement.

Introduction.

Public monies pay for 80 percent of the costs associated with end-of-life care in the United States. About 70 percent of those who die each year are covered by Medicare, and about 13 percent are covered by Medicaid, according to the National Hospice and Palliative Care Organization, so any discussion of reimbursement for end-of-life care must begin with these programs. Medicare reimburses 32 percent of all hospital costs,¹ and Medicaid is the primary payor for nearly 70 percent of all nursing home care. Other government programs, such as those in the departments of Veterans Affairs and Defense, also cover end-of-life care. Additionally, public monies pay for people who die without insurance or adequate personal finances.

In general, medical care at the end of life consumes 10-12 percent of the total health care budget in the United States. Twenty-eight percent of the annual Medicare budget is spent on the 5.9 percent of its enrollees who die each year. The Medicare Payment Advisory Commission (MedPAC) issued a preliminary report to Congress in 2000 on a comprehensive project that quantified costs to the Medicare program of care delivered during the last year of life; the report provides substantial data based on a retrospective look at end-of-life spending. "Medicare decedents in any year amount to about 4.7 percent of individuals entitled to Medicare during that year," the report says. "Medicare payments for the last year of life averaged just over \$26,000 (1997 basis), six times the per-capita cost for survivors. Spending for the last year of life was 25 percent of total Medicare outlays."²

While extensive data can quantify the costs of caring for severely ill individuals with unknown life expectancy, authors of even the most comprehensive and sophisticated studies admit they are not able to document the cost-effectiveness of the care delivered in anticipation of impending death. The MedPAC authors warn that "in no sense should the high costs (of health care) be taken as showing a high degree of wasteful or futile care ... (because) data on decedents' costs can be misinterpreted." The need, then, for public policy that is based on science and sound data is more pressing than ever.

The number of Medicare beneficiaries choosing hospice care increased significantly from 1992 to 1998, according to the U.S. General Accounting Office (GAO).² Hospice use has become typical for cancer patients in the Medicare program, to the extent that more than half of Medicare-covered cancer decedents in 1998 used hospice care.³ Of Medicare beneficiaries who died in 1998, about one in five used the hospice benefit. In Michigan, about 88 percent of hospice patients are Medicare beneficiaries, 8 percent are covered by Blue Cross and Blue Shield, 6.7 percent are covered by Medicaid, and 2.4 percent are uninsured. From 1992 to 1996, the number of people enrolled in Michigan hospice programs increased by 9,598; in 1996, 19,400 people died in hospice programs in Michigan, according to the Michigan Hospice and Palliative Care Organization (1998).

The Medicare hospice benefit was the first legitimate funding source specifically designed to provide comprehensive care to patients with life-limiting illness and to their families.⁴ Medicare has become the largest payor for end-of-life services and has also had a major influence on the shape of hospice care, serving as the model for increasing numbers of third party payors that

cover hospice services. Yet, while Medicare coverage of hospice care sets the standard for many third party payors, the fact is that this model for hospice reimbursement has not changed since its inception in 1982. Private and indemnity insurance, as well as health maintenance organization (HMO) coverage, are variable when compared to the Medicare model.

For example, many contracts with Michigan's Blue Care Network, an HMO, do not offer a traditional Medicare-model hospice benefit to its members, and many HMOs and managed care organizations do not formally offer hospice coverage in their contracts but will arrange for it by beneficiary request. There are further variations of coverage in the private sector related to services such as pain management and palliative care [see Table V(C)1].

Looking at all payors, Medicare is the largest payor for hospice services in the last year of life. Medicaid is the primary payor for nursing home-related services but it also covers acute care (hospital) and hospice for eligible beneficiaries at the end of life. Commercial payors primarily pay for acute care services, but they also cover some hospice services. Private-paying individuals as a group are buying private-duty nursing care in their homes, home health care, and nursing home care during the last year of life.

The Medicare model.

Many health care systems provide excellent end-of-life care and support services based on the Medicare model, but many people think some aspects of that model can be significantly improved. In its hospice benefit, Medicare covers physician services, intermittent nursing care, medical appliances, medical supplies, durable medical equipment, outpatient drugs for symptom management and pain relief, short-term inpatient care and respite, nurse aide and homemaker services, physical and occupational therapy, medical social work, medication, dietary counseling, chaplain services, and other therapy related to the terminal illness. Medicare's hospice benefit does not cover treatment of the terminal illness that is not for symptom management or pain control, care provided by more than one hospice, or care from another provider that duplicates the care the hospice is required to furnish.

The hospice agency receives payment for the spectrum of covered services at a per diem rate set by the federal Centers for Medicare and Medicaid Services (CMS). When it was established, the Medicare hospice benefit was one of the first examples of the capitated method of reimbursement for medical care, a system that is widely used by both commercial and government payors for end-of-life and many other services.

Medicare also reimburses for a range of services often associated with end-of-life care that are not part of the specific hospice benefit or palliative care services provided. Because they are not related to the terminal illness or diagnosis, these are reimbursed through the standard Medicare funding mechanisms. These include inpatient and outpatient hospitalization, chemotherapy, physician visits, consultations, surgeries, home health care, and some prescription drugs.

However, Medicare is rarely the only payor for its beneficiaries' health care needs. In 1992, Medicare covered about half (53 percent) of health care expenses in the calendar year of death, with the remaining 47 percent coming from Medicaid, private insurance, beneficiaries, and other sources. Later in the 1990s, Medicare was paying a larger proportion, totaling more than 60

Table V(C)1: Coverage of end-of-life services by public and private programs.

	Hospice	Pain management	Palliative care	Other end-of-life services
Medicaid and Medicare	Yes. Program must be licensed by the State of Michigan and Medicare-certified. Hospice services are formally defined in the Public Health Code.	No formalized, structured benefit. Individually covered services could be provided through a pain clinic or by other licensed health care providers.	No formalized, structured, benefit. Individually covered services could be provided by licensed health care providers.	No formalized, structured, benefit. Individually covered services could be provided by licensed health care providers.
Department of Veterans Affairs	Yes. Services can be provided through VA hospice, Medicare-certified hospice, or community volunteer hospice program.	Yes. VA medical centers offer assistance through the pain management director.	Yes.	Yes. Services provided through VA hospice program as needed.
Private health maintenance organizations (HMOs) or managed care organizations (MCOs)	Yes. Hospice must be licensed by the State of Michigan and hospice services are formally defined in the Public Health Code. There is no mandatory nationwide accreditation for hospice programs. The hospice program must have a contract with HMO/MCO. (Some HMO/MCO providers do not formally offer hospice coverage but will arrange for it by beneficiary request.)	No formalized, structured, benefit. Individually covered services could be provided through a pain clinic if the clinic has a contract with the HMO/MCO. Individual covered services could be provided by other licensed health care providers who are employees of or have a contract with the HMO/MCO.	No formalized, structured, benefit. Individually covered services could be provided by licensed health care providers who are employees of or have a contract with the HMO/MCO.	No formalized, structured, benefit. Individually covered services could be provided by licensed health care providers who are employees of or have a contract with the HMO/MCO.
Private indemnity insurance	Yes. Hospice program must be licensed by the State of Michigan. Hospice services are formally defined in the Public Health Code. No mandatory nationwide accreditation for hospice programs.	No formalized, structured benefit. Individually covered services could be provided through a pain clinic or by other licensed health care providers.	No formalized, structured, benefit. Individually covered services could be provided by licensed health care providers.	No formalized, structured, benefit. Individually covered services could be provided by licensed health care providers.

Sources: U.S. Department of Health and Human Services, U.S. Health Care Financing Administration, U.S. Department of Veterans Affairs, Michigan Commission on End of Life Care Insurance Survey 2000, Michigan Department of Community Health.

percent of all costs for Medicare-enrolled decedents, calculated for the calendar year of death, according to the MedPAC study.

Another major component of end-of-life costs not included in Medicare coverage is most oral prescription drugs. These must be paid by the beneficiaries' private insurance or the Medicaid program (for the approximately 13 percent who qualify), or they become out-of-pocket expenses to the individuals.

Medicare and hospice care.

Hospice coverage under Medicare was designed to allow an approved hospice agency to deliver care in the patient's home. For many years, end-of-life costs have "remained stable as a proportion of total Medicare outlays," according to the MedPAC study. "Medicare decedents in any year amounted to about 4.7 percent of individuals ever entitled to Medicare during that year," and spending for the last year of life was 25 percent of the program's costs. The Medicare hospice benefit was designed with specific limits on the cost of curative care; the medical model used was a solid tumor disease model, and the intent was to provide a service that would be of higher quality but have lower overall costs. Since the 1980s, however, chronic diseases have emerged as the major cause of death, and the trajectory of those diseases does not follow the solid tumor model used nearly 20 years ago.

Medicare coverage for hospice care, as determined by CMS, is very specific. It generally requires that reimbursement not occur unless two physicians have determined a person has a life-limiting illness that will be terminal within six months if the disease runs its normal course. Beneficiaries must waive all other Medicare coverage of care related to their illness in order to choose hospice coverage.

The six-month rule originated in the late 1970s, when researchers plotted the dates of people's deaths in relation to the dates they received their cancer diagnoses. The bell curve that resulted has a standard deviation of six months. However, many illnesses tend to be a good deal less predictable than cancer. Death due to heart disease, for example, is often sudden and difficult to predict, unlike death from cancer. It is difficult to identify which hospitalized patients with advanced congestive heart failure, chronic obstructive pulmonary disease, or end-stage liver disease will probably die within six months. In short, these diseases do not fit the Medicare reimbursement model for hospice care.

The Medicare six-month rule often comes under fire, and an increasing number of palliative care experts have called for its elimination. Because patients must sign a consent form recognizing that they are terminally ill and waive all other Medicare services that would possibly be curative, some health care professionals feel that many patients and families equate the word "hospice" with "no hope" and that this is reinforced by a "death culture" among some hospices and caregivers.⁵

Beneficiaries can cancel hospice benefits, return to regular Medicare, and remain free to choose hospice care again later. Before 1990, hospice programs were required to continue to provide services beyond 210 days without Medicare funding. In 1990, the 210-day lifetime benefit limitation was removed, and currently there are no limits on the number of days an individual can receive hospice care.⁶ Current regulations require that the prognosis be reaffirmed at 90 days, 180 days, and every 60 days thereafter.

While the number of Medicare beneficiaries using hospice care increased, the GAO study noted that the average stay dropped to 59 days in 1998 from 74 days in 1992. In Michigan, the average stay in 1998 was even shorter: 56 days, a 21 percent drop from 1992. Each year, according to the GAO report, 10-14 percent of beneficiaries choosing hospice care deselected or cancel their choice for the hospice benefit; beneficiaries with non-cancer diagnoses were more likely than cancer patients to do so. The national median length of stay in hospice programs in 1998 was 19 days, and in Michigan it was 21.5 days. Also, 28 percent of hospice beneficiaries across the country in 1998 used one week or less of hospice care. The primary cause of this short length of stay is late referral of patients who are at an advanced stage of their illness.

Many factors influence the use of the Medicare hospice benefit, including public and professional awareness and physician preferences and practices. Patients' entry into hospice programs may be a "sociobiologic phenomenon" since the average lengths of stay of hospice patients in the United Kingdom, Australia, New Zealand, Israel, and Canada are similar to those in the United States, despite different reimbursement systems.⁷ In fact, entry appears to depend on a "complex interplay of factors, such as the wishes of and communication between patients and physicians, physicians' practices such as prognostication, and the inherent trajectory of illnesses".⁸

In 1995, the Office of the Inspector General (OIG) joined with other federal agencies in Operation Restore Trust, an initiative to identify aspects of the Medicare program that were vulnerable to fraud and abuse. Hospice care was one of the services reviewed in five states. The OIG found a significant increase in the numbers of people in hospice programs beyond the 210 days and noted that many were people with chronic illnesses in nursing facilities. Nursing facility residents were found to account for the majority of patients determined to be ineligible for hospice care, often with diagnoses such as senility.

As a result of the OIG findings, modifications were made to the Medicare hospice benefit in 1997. Hospice programs were thereafter allowed to discharge patients whose condition had improved without fearing loss of future hospice benefits, and they were also required to document more frequent certifications of eligibility after 180 days of care.

Some believe that the increased federal regulation has effectively limited access to hospice programs and created fear in hospice providers and referring physicians of their potential liability for fraud and abuse.⁶ It is possible that some hospice providers have responded by adopting more conservative criteria for admission into their programs.

Reimbursement for hospice services.

Under the Medicare hospice benefit, a hospice provider is paid an all-inclusive, prospectively determined rate for each day a beneficiary is enrolled. Initial rates were based on cost data collected during the Medicare demonstration program in the early 1980s. Since 1993, the rates have been linked by statute to inflation in the cost of goods and services purchased by hospitals nationwide. The daily base payment rates for fiscal 2000 were \$98.96 for routine home care, \$577.59 for continuous home care, \$102.37 for inpatient respite care, and \$440.22 for inpatient hospital care (GAO, 2000).

Factors in the Medicare hospice rate include hospital wages, which are no longer relevant to hospice care. Costs of prescription drugs have increased much faster than the medical inflation index, with new pain-relief medications coming on the market. When the original hospice benefit was determined, drugs for pain relief and symptom management, the cornerstones of hospice care, were only 3 percent of costs. Prescription drugs now account for 50 percent of hospice expenses.

The original Medicare hospice benefit was based on 70 days of care, but the average duration of hospice care has dropped to 40 days. Since the cost of care increases toward the end of life, the average cost per day is much higher when the number of days in a hospice program is lower.

Since 1982, when Medicare designed the methodology for determining the base rate for hospice care, rates have not kept pace with changes in end-of-life care practices. Many believe that Medicare hospice reimbursement should take into account the actual costs associated with current compassionate approaches to caring for the dying and their families.

Several studies have looked at hospice care and cost savings, mostly with mixed results. It is estimated that in the last month of life, home hospice care saves between 31-64 percent of medical care costs, accounted for mostly by reduced hospital services. However, the longer a patient is in a hospice program, the greater the likelihood of complications and associated cost increases; the costs could easily exceed those received as a part of the hospice rate, which are based on conventional-care patients.⁹ These extraordinary costs are called outliers. Some believe that a more equitable system for hospice providers who care for large or disproportionate numbers of patients needing higher cost services would incorporate such outliers in rate determination methodologies.

The MedPAC study of Medicare beneficiaries' costs at the end of life demonstrated that:

...there was no statistically significant difference in total costs (including all sources of payment) between decedents who did and did not use hospice. Medicare's payments, by contrast, were higher for hospice users. As a result, Medicare paid a significantly higher share of costs for hospice decedents. This simple analysis did not adjust for factors such as diagnosis and patient self-selection, as was done for the formal evaluation of the Medicare hospice benefit.

Although diagnoses and patient self-selection undoubtedly affect hospice costs, lack of unexpected deaths in hospice may also play a part. One-quarter of non-hospice decedents had spending below \$5,000, but only 7 percent of hospice decedents did. Those who died without substantial medical care in the last year of life are far less likely to appear as hospice patients.

While hospice enrollment is often linked to reimbursement issues, several studies have drawn different conclusions. In a study of more than 220,000 Medicare beneficiaries enrolled in hospice programs, the median survival was only 36 days; 15 percent of the beneficiaries died within a week, and 28 percent died within 14 days. Most patients with the hospice benefit enter hospice care late in the course of their terminal illness, which defeats the hope for the "good death" that hospice programs espouse.¹⁰

A study of 917 adults with advanced, metastatic lung or colon cancer drawn from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (the SUPPORT study¹¹) found that patients who thought they were going to live for at least six months favored life-extending therapy over supportive care. Compared to their physicians, patients may overestimate their six-month survivability and believe that aggressive treatment will cure them.¹² Funded by the Robert Wood Johnson Foundation, the SUPPORT study, conducted in teaching hospitals nationwide, involving more than 10,000 patients and costing more than \$23 million, was pivotal research that provided valuable information on intensity and appropriateness of acute and extensive care in the last six months of life. The investigators concluded that physicians are not skilled at predicting dates of their patients' death, even one day before they die, and that physicians, through their orders, are therefore high utilizers of end-of-life care services.

Palliative care.

Palliative care refers to a comprehensive management of patients' physical, psychological, social, spiritual, and existential needs.¹³ Palliative care seeks to relieve the suffering of terminally ill patients and their families and can complement other therapies. This means that a patient approaching the end of life and receiving palliative care would not be required to give up curative care, such as chemotherapy, as is required when agreeing to receive hospice services. Palliative interventions tend to increase as illness progresses, rather than starting when one phase of treatment ends.

Palliative care seeks to bring together the clinical expertise of physicians and members of the patient's health care team so that services and treatment are ordered that are consistent with the patient's personal needs and goals. The philosophy of this specialty is that any treatment is appropriate when it is in line with the patient's needs and desires. The result is high patient satisfaction and possibly cost-effectiveness, rather than elimination of therapies or services as the only measure to cut health care costs. This patient-centered approach does not seem to adapt well to any kind of existing reimbursement model, but there are studies that have demonstrated that palliative care can fit into the strict rate-setting world of third party payments and actuarial computations.

This area of medicine has evolved recently, with its genesis in academic and acute care hospitals. It has become an area of special expertise within medicine, nursing, and the allied health professions but has not been fully integrated into standard clinical practice or the reimbursement system. This has made it difficult for providers to obtain reimbursement for this relatively new set of services. Interest is developing, in fact, to use various funding streams for care for those patients dying in hospitals.

Currently there is no formal recognition of palliative care specialists or palliative care units in hospitals, but according to the American Board of Hospice and Palliative Medicine, 41 physicians in Michigan have passed the certification exam in hospice and palliative medicine and 44 hospitals in the state have organized various types of palliative care units.

Reimbursement. Palliative care services or units are typically hospital-based. With the majority of deaths in the United States now occurring in hospitals, the CMS approved a diagnostic code for palliative care in 1996. To be used as a research tool, frequency of use of the new code was to be tracked and changes made accordingly. In creating the new code, it was recognized that hospice care is not the only answer for dying patients and that significant changes in end-of-life care still must occur in hospitals as this area of health care continues to evolve.¹⁴

Medicaid.

Hospice care. The CMS does not mandate that state Medicaid programs include hospice coverage in their plans, but Michigan has provided this benefit for many years. In order to receive reimbursement, providers must be licensed by the state and demonstrate that they meet Medicare standards for reimbursement. Michigan's Public Health Code defines hospice services, so patients have additional statutory protection.

The Michigan Medicaid hospice benefit must essentially follow the CMS regulations, so it closely resembles the Medicare benefit. The "six-month rule" is in effect, and participants must waive all curative care.

Long-term care — nursing facilities. Under federal law, all state Medicaid programs must cover long-term care services. The federal definition of long-term care includes "nursing facility and home health services for persons age 21 and older", but Michigan covers many other long-term care services for people of all ages, including those who are elderly, disabled, or mentally retarded or who have developmental disabilities. The Michigan Department of Community Health defines long-term care to include the costs of nursing homes, home health, medical care facilities/chronic care units, personal care for adult foster care residents, and personal care for in-home residents. For purposes of quantifying the coverage for those who need end-of-life services, however, it is most practical to focus on nursing facility coverage.

Medicare and Medicaid pay more than 60 percent of all reimbursement for nursing facility care in this country. In Michigan, the Medicaid program in MDCH pays for 70 percent of all nursing home care, while Medicare pays for 10 percent. In fiscal 1998, Michigan Medicaid paid at least part of the nursing facility costs for more than 45,000 people. (MDCH, spring 1999). The long-term care policies are some of the most complex and expensive components of the Medicaid program. In fiscal years 2001 and 2002, one-fourth of Michigan's medical services appropriation was allocated for long-term care services. In an MDCH budget of \$8.77 billion for fiscal 2002, Medicaid funding for long-term care exceeded \$1.4 billion, with another \$10 million appropriated from tobacco settlement funds for innovation long-term care grants (MDCH, March 2001).

Generally 3 to 5 percent of people age 65 and older are admitted to a nursing home in this country each year. The lifetime risk of admission to a nursing home for people this age is about 45 percent for women and 28 percent for men. Predictors of entering a nursing facility are being older, a woman, white, and living alone; lacking social support; having physical and mental impairment or limitations in the ability to perform activities of daily living; the presence of specific medical conditions; previous stay in a nursing facility; and not being the primary person making decisions.¹⁵

Several years after the Medicare hospice benefit was enacted, it was modified to include patients living in a nursing home — but only if they paid for their own care or were in the nursing home under the Medicaid program. This change occurred because the hospice benefit was intended to be used by people in their homes, with a provision for brief periods of inpatient hospital services.⁴

For most nursing home residents, the nursing home has become their home. This aspect of Medicare hospice coverage has forced many families to make the difficult choice between hospice and nursing homes. In addition, as Kinzbrunner reports, the essence of the problem is in the conflict of the goals of two providers — nursing homes and hospice. The mandate to nursing homes is to provide services that “attain or maintain the patients’ highest practicable physical, mental and psychosocial well-being,” an outcome that generally contrasts with that of hospice.³

Reimbursement methods. Each nursing facility in Michigan has its own daily rate for Medicaid residents. It is a prospective payment system based on the type of nursing facility it is and on its annual costs. Unlike Medicare, Michigan Medicaid does not reimburse per resident based on the severity of the residents’ condition.

Commercial insurers.

In the fall of 2000, the Commission’s Insurance Project Work Group developed and conducted a statewide survey of insurers, including all commercial insurers and not-for-profit health care corporations, to investigate and analyze specific issues concerning private and public insurance coverage related to end-of-life care in Michigan. The work group also reviewed relevant publications and met with local and state experts on insurance and end-of-life care. (*See the complete report in VIII E*).

One of the key findings of the literature review was that many physicians are not aware that the current coding system used to bill third party payors for hospice and palliative care includes codes related to such care.⁴ Most beneficiaries also lack an understanding of what their health plans cover and do not cover for end-of-life care. For example, only 36.5 percent of adult respondents said their insurance covered hospice care, while 52.5 percent did not know if their insurance covered hospice care, according to the 1999 Michigan Behavior Risk Factor Survey conducted by MDCH.

Commercial and indemnity insurers account for less than 20 percent of end-of-life care, but they still have a major impact on spending of health care dollars. The survey’s findings only reiterate the need for consideration of standards for comprehensive end-of-life care benefits, while allowing flexibility for competition and innovation.

Discussion.

In Michigan, Medicaid reimbursement is based on the Medicare model, so it comes as no surprise that the problems that exist in the Medicare hospice benefit also exist in the Medicaid hospice benefit. Indemnity insurance plans and health maintenance organizations vary in the coverage offered to enrollees. Recommendations for reform must address all three streams of hospice reimbursement as well as the need for palliative care before the last six months of life.

A better measure of when to initiate appropriate end-of-life care is when the patient's functional status deteriorates and the person is "frail." Research conducted by Catherine Eng, MD, in the Program of All-inclusive Care for the Elderly (PACE) On Lok organization, which provides services for the well-being of more than 800 elderly and their families in San Francisco, determines frailty as the point at which a person meets one or more of the following criteria:

- Is dependent in three activities of daily living
- Has cognitive impairment plus dependency in one or two activities of daily living
- Is in the advanced stages of a chronic disease such as congestive heart failure, chronic obstructive lung disease, or diabetes mellitus; makes frequent visits to the emergency room
- Has had more than one hospital stay within six months.¹⁶

Research, in a variety of forms, is needed to document and provide a scientific basis for the changes under consideration, but much research has already been conducted that demonstrates best practices ready for implementation in the short term.

Still, achieving real and lasting change requires a systems approach that can only come from a long-term public-private stakeholder coalition. This type of approach was used in the last century when the public highway and road system was put into place. Our integrated highway system could not have been achieved without public-private cooperation over several administrations. The same type of approach is needed to develop a new health care delivery system that incorporates both curative and palliative care for the citizens of Michigan. Fundamental changes such as these would also eliminate access barriers to high-quality end-of-life care and supports.

Changes in the system will provide more health care benefits to employers and even the greater community. Appropriate palliative care services provide relief of the physical and emotional caregiving burden of the family. Healthier family caregivers have lower overall health care costs. In addition, when family members have adequate supports, there is less physical and emotional stress from caregiving, and productivity at work is maintained.

Recommendations.

The committee makes the following recommendations related to reimbursement for end-of-life services:

1 MDCH should assess and validate existing Michigan data to determine how to optimize care at the end of life by analyzing, redistributing, and redesigning incentives in order to provide more options concerning types and settings of care.

Rationale.

Many aspects of the health care delivery system for end-of-life care are no longer based on current science but are geared to outcomes that are provider-centered rather than patient- and family-centered. Reimbursement incentives, for example, focus on over-treatment and keeping people alive long after a cure is possible; this results in hospitals and physicians treating patients more aggressively than is necessary or desired by the patients. The first goal should be to realign reimbursement incentives so that providers will deliver the right level of service at the right time in consultation with informed patients and families.

There are also gaps in insurance coverage and other reimbursement for some end-of-life services. Patients and families with indemnity insurance or HMO coverage have a significant administrative burden in processing claims from hospitals, doctors, laboratories, and radiology centers, and these providers are frequently in conflict with one another as to what is covered or paid for.

2 The Governor's Office, MDCH, and the Michigan Department of Consumer and Industry Services should work with the Michigan Congressional delegation and federal agencies to further understand and explore current or proposed federal laws and regulations for Medicare and Medicaid to determine the impact, particularly in Michigan, and make changes where appropriate, in the following areas:

- a) Development of an outlier formula for hospice programs that serve a large number of patients who need higher-cost services such as pharmaceuticals, palliative radiation or chemotherapy, durable medical equipment, blood transfusions and products, or require such services in settings in where significant transportation costs exist
- b) Development of an acuity-based reimbursement formula for the first and last days in hospice in light of the rapidly declining length of stay, which creates an increasing proportion of high-cost days
- c) Amending the 20 percent limit on inpatient hospice days in relation to total hospice days for those hospice programs that can document service to a disproportionately large number of high-acuity patients
- d) Modifying the Medicare hospice benefit by creating a financially neutral reimbursement methodology for nursing home hospice care so that Medicare beneficiaries can choose hospice care without penalty to the nursing home or eligible residents. [*see also recommendation #7 of the Long Term Care Work Group at V(D)*].
- e) Consideration of reimbursement for palliative care providers, including physicians, nurses, social workers, spiritual care counselors, bereavement counselors, and other allied health professionals, to meet patients' and families' end-of-life needs.

Rationale.

There is a lack of comprehensive coverage for end-of-life services based on current models of care, changes in therapeutic modalities, significant inflation of drug prices, and today's finances. The hospice reimbursement model, based on studies done in the 1970s and 1980s, is outdated and does not cover multidisciplinary palliative care consultations or bereavement services.

The cost-effective design of the national hospice benefit — the “six-month rule” and economical home care — has discouraged delivery of inpatient hospital palliative care. In addition, patients and families must “give up hope” by admitting that the patient's illness is terminal in order to gain access to the comprehensive services that a hospice program provides.

Reimbursement of pediatric hospice care has serious gaps based on the trajectory of chronic illness in children.

Disincentives exist for nursing homes that offer the hospice benefit to their residents because it puts the nursing homes in the position of having to abide by two sets of state regulations, one that focuses on rehabilitation and another that focuses on end-of-life care. Furthermore, when there is a lack of coordination of service or a problem with the care plan, it is the long-term care facility that receives the citation, not the hospice program.

Federal nursing home quality assessments and reimbursement incentives both emphasize restorative care while failing to reward high-quality palliative care. Administrative and contractual barriers, plus suspicion of fraud or “double-dipping”, limit hospice care in long-term care settings. Since long-term care facilities are an increasingly important site for terminal care, it is reasonable to anticipate growing demands for palliative and hospice care in these settings. Changes in current incentives and policies could be used to promote the appropriate use of palliative care for people who live the final phase of their lives in a nursing facility.

Nursing homes are given an incentive to provide restorative care that frequently is at odds with quality end-of-life care and are regulated accordingly, and hospitals and physicians are given an incentive to continue expensive and often futile treatment in order to maintain their revenue streams.

At another level, families often face their own financial disincentive to having loved ones admitted to nursing homes for hospice care because they have to pay for the room and board charge if the patient does not qualify for Medicaid.

3 MDCH should review the final report of the Hospice Residence Research Project to determine if funding the room-and-board component of inpatient hospice residences is a cost-neutral means of delivering patient care.

4 The Legislature should encourage and fund research projects designed to evaluate the hypothesis that offering both curative and palliative services concurrently is cost-effective.

Rationale.

The state Legislature should appropriate funds to this end, and MDCH should coordinate and bring together a long-term coalition of stakeholders, including representatives of the public and private sectors, to design innovative demonstration projects that reshape health care delivery systems to provide appropriate curative and palliative care services. The services will be designed around the needs of patients and families rather than those of the providers of services, will eliminate barriers to access, and will realign financial incentives so that providers deliver the right service at the right time.

The Legislature should fund public and private demonstration projects that incorporate palliative care earlier in the course of a patient's chronic disease in order to realign current health care spending to fund appropriate care earlier along the curative care-palliative care continuum. The appropriate setting for care delivery will be based on the patient's condition, palliative care assessment, and self-determination of care requirements. The results should be offered to researchers and health care systems.

Those involved with palliative care believe payors need to become more skilled at fitting their benefits to the needs of their beneficiaries and their beneficiaries' families. This can be accomplished by establishing accurate triggers for physicians to use at the end of a patient's life in order to help them decide when to switch from purely curative care to palliative care. Palliative care specialists envision a shift in the thinking of providers and payors to seeking best treatment options in consultation with patient and family instead of choosing treatment options based on traditional medical practice or provider education, all of which are provider-centered rather than patient- and family-centered. Possibly a better measure of when to initiate end-of-life care is when the patient's functional status deteriorates and the person is "frail."

5 Health plans and payors should be encouraged to pay the reasonable cost of pain and symptom management (including generic substitution where pharmacologically equivalent and clinically appropriate), for palliative care consultations, and for non-pharmacological treatment of pain and symptoms by all types of providers, including physicians, nurse practitioners and members of other disciplines.

Rationale.

Currently, many believe that reimbursement is inadequate for palliative care interdisciplinary consultation (i.e., nurse, social worker, spiritual care counselor, and grief support counselor — not just the physician).

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V(D). Long-term care.

The Commission appointed a committee to study end-of-life care given Michigan residents living in long-term care settings. An evaluation of the current literature, a review of the report and recommendations of the Michigan Long Term Care Work Group, theme analysis generated from public hearings, and consultation with professional and political experts have produced the following report and recommendations.

Long-term care populations.

The elderly. People 65 years old and older represent one of the fastest-growing segments of the population. In 1995, the elderly comprised slightly fewer than 13 percent of the population (34 million); by 2040, they will comprise 20 percent. In Michigan, the elderly comprise 12 percent of the population. The number of people 85 years old and older (the segment most likely to need long-term care) will triple in size by 2040.

In 1995, an estimated 12.8 million people in the United States reported long-term care needs. These needs increase substantially with age. Among all elderly people, 5 percent live in nursing homes and 12 percent live in the community with needs for assistance with activities of daily living (ADL) such as eating and bathing or with instrumental activities of daily living (IADL) such as housekeeping and meal preparation. Among those 85 and older, 21 percent live in nursing facilities and 49 percent live in the community with long-term care needs.¹

People with disabilities. One of every five Michigan residents (approximately 2 million) has a disability. Adults with disabilities make up the fastest-growing segment of the long-term care population, and in 2000, about 8 percent (6,846) of the people in Michigan's nursing homes were younger than 65. In Michigan's Medicaid programs for community-based care, the approximately 3,400 non-elderly adults with disabilities make up 24 percent of the participants in the Medicaid MI Choice home and community-based waiver program and 55 percent (some 20,300 people) of the Home Help program.

People with dementia. As the population ages, the proportion of people with dementia also increases. For people age 65-69, the rate of moderate to severe dementia is about 2 percent; for people age 70-74, the rate is 4 percent; for people 75-79 the rate is 8 percent; and for people older than 85, the rate is 16 percent, according to the U.S. Department of Health and Human Services Administration on Aging (AoA) as reported in 1998. In Michigan, 250,000 people have Alzheimer's disease or related dementia disorders.

People at the end of life. In 1998, 19,695 Michigan residents died in nursing homes, an increase of 61 percent (from 12,199) in 1990. Deaths at home increased 41 percent, to 21,818 in 1998 from 15,507 in 1990. Deaths in hospitals dropped 13 percent, to 40,466 in 1998 from 46,398 in 1990. In 2000, hospice organizations in Michigan reported serving over 26,000 people.

Long-term care settings.

Long-term care in Michigan occurs in a variety of settings. Among the elderly at greatest risk for nursing facility placement (i.e., those with three or more ADL limitations), 86 percent live with others and receive about 60 hours of informal care per week, supplemented by about 14

hours of paid services. Nationally, this informal care has been valued at between \$45 billion and \$94 billion annually (AoA, 1998). Other estimates are much greater, when calculating all costs related to families who provide free, informal care. A 1999 study¹ showed the value of such care to be \$200 billion annually. The report labeled this informal caregiving system “the vast but vulnerable base upon which our chronic care system rests”. The value of such services dwarfs the budgets of all publicly funded long-term care programs. If it were to collapse, the effects are frightening, and unpaid caregiver burnout often is the reason a family member is institutionalized in the first place.²

Community-based care. More than 80 percent of the elderly with limitations in their ADL or IADL, live in the community. Sixty percent have disabilities only in IADLs, while 17 percent are considered severely disabled, with limitations in three or more ADLs.³ About 20,000 home health care organizations and hospices serve 8 million people in the United States each year. In Michigan, the MI Choice home- and community-based waiver program serves 15,000 people annually, and the Home Help program serves 37,000 people each month. MI Choice provides nursing-home levels of care, while the Home Help program generally provides services to individuals with less extensive needs.

Nursing facilities. There are 17,000 certified nursing facilities in the United States, serving 1.5 million people. The nursing facility population is becoming more severely disabled; a 1987 study found that 33.3 percent of nursing facility residents had five ADL limitations, while a study conducted in 1996 found that more than 50 percent had this level of limitations. The same research found the nursing home population to be more cognitively impaired.⁴ Michigan licenses more than 450 nursing facilities that serve more than 150,000 people who require some degree of nursing facility care each year.

Homes for the aged and adult foster care. These settings provide room and board with varying levels of care. Michigan has about 4,450 licensed adult foster care homes, with some 33,750 beds, and 169 licensed homes for the aged, with about 12,800 beds.

Assisted living. There are 28,000 assisted living facilities in the United States, serving 600,000 people. Because assisted living is not regulated in Michigan, it is difficult to obtain comprehensive information on the number of facilities. Michigan has an estimated 25,000 assisted living beds.

Findings.

The Committee on Long-Term Care has reached the following conclusions concerning long-term care in Michigan:

- Delivery of pain and symptom management care for Michigan residents living with advanced illness in long-term care settings is inadequate.

Current data suggest that pain and symptoms of residents at the end of life are prevalent in nursing facilities but such discomfort is likely to be substantially underestimated. The philosophical dichotomy between nursing facilities’ goals of rehabilitation and the intent of palliative care interferes with a patient’s quality of life as death becomes imminent.

- Health care professionals and aides are seldom instructed in pain and symptom management and therefore may not be addressing the complex issues that interfere with quality of life. Furthermore, physicians are often reluctant to prescribe the appropriate medications because of regulatory issues and the lack of professional knowledge.

The underestimation of pain and symptoms that interfere with a resident's quality of life in long-term care settings is well documented in the literature. This problem and the lack of the professional education and clinical skills required to relieve the symptoms that accompany both advanced illness and death require policy-makers' attention. The current regulatory restrictions inhibit prescribing physicians in their use of appropriate medications to control symptoms.

- Referral and access to end-of-life care are often limited for residents of long-term care facilities. Financial disincentives and philosophical differences often interfere with expert pain and palliative interventions.

Residents who receive the Medicare hospice benefit in a long-term care setting account for only one percent of all hospice beneficiaries in the U. S.⁵ National data suggest that access to hospice care in nursing homes varies markedly by region, and 70 percent of long-term care settings have no hospice patients.⁶ Federal policy and regulations emphasize rehabilitation and restoration of function as the goals of care, and federal nursing home quality assessments and reimbursement incentives both emphasize restorative care while failing to reward high-quality palliative care.⁵

Michigan residents of long-term facilities who have advanced illness or are dying, deserve quality end-of-life care. Early conversations and documentation regarding advance directives may identify a person's preferences for care, but high-quality end-of-life care includes much more than advance directives. Palliative services intended to reduce pain and other physical discomfort, improve functioning, and help resolve issues of life closure such as spirituality and letting go are not being fully utilized.⁷

Recommendations.

The Committee on Long-Term Care makes the following recommendations:

1 The Michigan Department of Consumer and Industry Services (MDCIS) and the Michigan Long Term Care Work Group (LTCWG), together with providers of long-term care, should continue their work to address barriers that interfere with quality end-of-life care. These include:

- Confusion and conflict around the interpretation and enforcement of regulations dealing with avoidable and unavoidable decline, and the reluctance to use medications that are perceived to interfere with function, such as psychotropic or opiate medications for terminally ill patients
- Lack of adequate pain and symptom management
- A focus on restorative, rehabilitative care as opposed to palliative, comfort care that recognizes the functional decline associated with the dying process
- Disincentives for long-term care facilities to offer hospice and palliative services to their residents

- Absence of best-practice models for palliative end-of-life care unique to long-term care settings.

Rationale.

Catalysts for change include an awareness of the need for action as well as the tools and resources to implement new behaviors, methods, or technologies. Based on public testimony, current literature review, and research, as well as communication with professionals and the public, this committee has identified key areas for improvement in the delivery of end-of-life care in the long-term care setting.

Testimony at public hearings and the experiences of both professionals and the public, support the need for action. In addition, long-term care settings are the site of a significant number of deaths. In 1998, 19,695 (23 percent) of Michigan residents who died did so in a long-term care facility. Long-term care facilities are expected to be the site of death for 40 percent of the population by 2020.

The committee also identified valuable tools and resources for improvement at both the national and state levels. What is needed is to use what is already known about the methods and means to relieve pain and suffering at the end of life. In the main, this committee's recommendations focus on making it easy to "do the right thing" by helping professional care providers become proficient at pain and symptom management; by removing financial barriers; by creating an environment that rewards innovation and best practices; and by helping the public learn how to manage end-of-life issues, with support for the use of advance directives and health care proxy instruments.

- 2 MDCIS and the LTCWG should develop educational and learning opportunities in end-of-life care for state surveyors of long-term care facilities, particularly on issues surrounding avoidable and unavoidable decline related to the naturalness of dying.

Rationale.

Surveyors of long-term care facilities evaluate and interpret facility compliance with regulations that are structured to require facilities to assess and evaluate patient care needs, intervene if necessary, and document efforts to maintain and/or improve function. Against that background, conflicts arise when the resident chooses to forego restorative care or the facility has not provided care that meets "acceptable standards" in the eyes of the surveyor.

Education is needed that will provide surveyors with a framework to use to evaluate the appropriateness of interventions for care at the end of life. Through the survey process, surveyors also have the opportunity to educate the facility staff concerning the importance of documenting the goals of care and the reasons for employing comfort measures as opposed to aggressive or intrusive therapies.

- 3 The Michigan Department of Community Health (MDCH), MDCIS, and the LTCWG should adopt by regulation the requirement that all state licensed long-term care settings incorporate and comply with the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) Long Term Care Pain Management Standards.

Rationale.

Implementation of standardized assessment of the multiple symptoms that accompany both advanced illness and dying and the provision of competent, evidence-based interventions will improve both patient outcomes and competencies of care, promoting a “good death” for the patient and family and an improved care environment.

4 MDCH, MDCIS, and the LTCWG should facilitate the utilization of advance directives and durable power of attorney for health care forms for all nursing facility residents by requiring that providers demonstrate and document efforts to engage residents in advance care planning discussions and that they update advance directives with any change in the resident’s status.

Rationale.

Discussion of future care plans and advance directives should be part of care planning for all patients admitted to a long-term care facility. This discussion can help clarify concerns patients and families have regarding the meaning of such decisions and help patients or their designated patient advocates or guardians clearly spell out their wishes about end-of-life care. Having these important conversations early in the process will reduce the need to make critical decisions in a moment of crisis.⁸

“There is too little or nothing to lose in initiating palliative care discussions earlier and more systematically in a patient’s final trajectory, and so much is lost when these discussions are avoided.”⁹ A number of studies have highlighted the importance of discussions among patients, their surrogates, and clinicians regarding options and preferences for current and future care. Significant data suggest that effective communication between patients and their health care providers can improve and enhance patient and family satisfaction.¹⁰

Advance directives are not an end in themselves but should be seen as part of the process that includes ongoing communication about the goals of care and the development of a contingency plan that will ensure both that care preferences will be honored and appropriate palliation provided.¹⁰ This shift in thinking is a move from simply complying with the Patient Self Determination Act of 1990, to having meaningful conversations and addressing the issues that surround intubation, tube feedings, resuscitation, and hospitalization. These early and ongoing discussions also identify patient preferences for palliative intervention and promote the specialty of palliative care within the long-term setting.

5 MDCH, MDCIS, and the LTCWG should create incentives for instruction in palliative care for physicians, pharmacists, nurses, social workers, and nursing assistants who provide services to residents of long-term care facilities. Facilities that demonstrate best practices in end-of-life care such as increased utilization of palliative care and hospice services and improved performance in the management of pain and other symptoms can serve as sites for such instruction and consultation.

Rationale.

Approximately 20 percent of Michigan long-term care facility residents will die each year. Public hearing testimony given by professionals, caregivers, and others indicated that there is a significant lack of pain and symptom management for residents living and dying with advanced illness. This testimony and the current literature indicate that the inadequate

assessment and undertreatment of pain and symptoms in nursing homes is a major public health problem in the United States.¹⁰

Inadequate pain and symptom management can often be traced to failures in assessment. A study of more than a half-million nursing home patients from 11 states revealed that nearly one-sixth of all nursing home residents reported to be in daily pain. Among residents diagnosed with cancer, slightly more than one in five are in daily pain. At least one in 11 nursing home residents experience persistent daily pain. Nearly one-quarter of all those in pain received no analgesia, not even acetaminophen or aspirin.¹³

Many believe that these statistics are explained by the fact that health care professionals are inadequately educated in pain and symptom management. They may not realize that the patient is uncomfortable, and they often fear prescribing opiates and other medications because of regulatory scrutiny. Yet the costs of unrelieved pain and symptoms for the patient are associated with a wide range of serious problems, including depression, decreased socialization, sleep disturbance, decreased mobility, falls, cognitive dysfunction, and malnutrition.

6 Long-term care providers should develop initiatives for improving end-of-life care in their facilities by identifying opportunities for quality improvement activities, implementing strategies for sustained improvement in the management of residents' pain, and partnering with palliative care providers, consultants and hospice programs to enhance services available to terminally ill residents.

Rationale.

Without measurement, no sustainable improvement in quality can take place. Providers and regulators need to take the first step in improving pain and symptom management by evaluating how existing mechanisms can be put to use to achieve quality outcomes. Data that are already collected and archived can be used to establish benchmarks for the measurement of pain, while tracking the effectiveness of interventions. The Brown University study of pain in the nursing home setting recommends that, "persistent pain should be a quality indicator that is reported publicly."¹³ It is particularly important that the frail elderly with cognitive impairment be properly evaluated for pain and other symptoms.

Long-term care facilities should be encouraged to use the resources available through palliative care and hospice care providers and to develop collaborative and partnership arrangements as often as possible.

7 The Governor and the state Legislature should endorse modification of the Medicare hospice benefit by creating a financially neutral reimbursement for nursing home hospice care under Medicare, so Medicare beneficiaries can choose hospice care without penalty to the nursing homes or to eligible residents. [*See also recommendation 2(d) of the Reimbursement Committee at V (C)*].

Rationale.

Federal nursing home quality assessments and reimbursement incentives both emphasize restorative care while failing to reward high-quality palliative care. Administrative and

contractual barriers, plus suspicion of fraud or “double-dipping”, limit hospice care in long-term care settings. Since long-term care facilities are an increasingly important site for terminal care, it is reasonable to anticipate growing demands for palliative and hospice care in these settings. Changes in current incentives and policies could be used to promote the appropriate use of palliative care for people who live the final phase of their lives in a nursing facility.

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V(E). Decision-making for the end of life.

Health care at the end of life usually provokes discussion of situations to be avoided, followed by examples of the confusion that exists in determining when treatment is no longer desirable. Almost everyone has some experience with the death of a loved one, and often, personal preferences for one's own death are based on those circumstances. One national study of the public's views of end-of-life care provides an important perspective.

***Quest to Die with Dignity* report.**

The Quest to Die with Dignity: An Analysis of Americans' Values, Opinions and Attitudes Concerning End of Life Care is the distillation of 36 focus-group discussions held around the United States. This study was funded by a grant from the Robert Wood Johnson Foundation to American Health Decisions, a national coalition of citizen groups concerned about ethical issues in health care.¹ Several key messages were gleaned from the focus groups, and many of them are reflected in the public testimony received by the Commission (*see Appendix VIII.B*).

Many people fear reaching the end of life hooked up to machines; others are worried that treatment will be denied. The focus groups held around the country for this research documented personal experiences of illness and death of family and friends. People expressed fear not just of dying, but of how they will die, and they expressed concern that the health care system is unresponsive to the needs of those who are dying. Focus group participants said the system does not seem to be structured to care for the dying, and they pointed to some of the issues discussed in this report as examples, e.g., pain and symptom management and reimbursement. The Commission received considerable testimony about the need for pain and symptom management, the importance of educating medical professionals in pain and symptom management, and the importance of improving the quality of life, both mentally and physically, for those with terminal illness.

While people in the focus groups said they wanted control over what happens to them at the end of life, they were reluctant to take the steps needed to achieve that control. The reasons cited were familiar: it's depressing, talking about death will make it happen, dying is in the future, and it's hard to discuss. The Commission received testimony that confirms the national estimates that fewer than 20 percent of adults have completed an advance directive document.

Dying can be a complex process, and the role of advance directives creates confusion for many people. The American Bar Association's (ABA) Commission on Legal Problems of the Elderly addresses some of the myths about advance directives.² Americans want the opportunity to recover, if recovery is possible. A physician testified to the ABA Commission of being willing to continue life-sustaining treatment if there would exist the possibility of the patient's status improving. Many people would be in favor of a "trial run" of some life support measures if their situation could improve but would want the treatment withdrawn if there were no improvement. The difficulty comes in determining when treatment shifts from saving a life to prolonging a death.

The *Quest to Die with Dignity* report identified seven values shared by all demographic groups among the focus group participants. They are ranked in order of frequency of response:

1. Freedom/independence
2. Trust
3. Compassion
4. Spirituality
5. Family consideration
6. Responsible planning
7. Societal responsibility.

Freedom implies free choice, a lack of constraint on individual decisions and actions. Independence suggests an autonomous life, not relying on external resources. This value carries the concern for individual rights and was often mentioned in reference to power issues.

In matters requiring trust, participants trusted their family more than their physicians to know what to do. Respondents viewed advance care planning and advance directives as a “family matter,” something shared with loved ones who are trusted. Mistrust of doctors and their motives emerged; some respondents worried that physicians would order complex care to obtain higher reimbursement, while others expressed concern that they would feel pressure to halt medical care in order to reduce costs.

Many participants were suspicious that advance directives could compromise their care by encouraging the withdrawal of life-saving treatments. “Americans clearly want a chance to recover when recovery is possible,” the report said.

Ending curative or rehabilitative care is a very difficult decision for any person, family, patient advocate or guardian. Unless a person expresses preferences about health care treatment and communicates those choices to family and health care professionals, whether formally through advance directives or through a series of conversations, others may be forced to make the choices. Further, an advance directive does not guarantee that individual wishes will be followed, but it increases the likelihood that it will occur. At one of the public hearings held by the Michigan Commission on End-of-Life Care, an attorney expressed this dilemma by emphasizing that whatever you have written down about your wishes is going to help those who have to decide.

From health care providers’ perspectives, remaining informed about and complying with advance directives for all their patients represents a challenge. Patients are treated by a multitude of providers in hospitals, outpatient offices, and home settings. Assuring wishes are followed is complicated when patients are transferred from one setting to another. Problems such as unwanted transfer and intensive medical interventions may occur for patients who did not want such interventions.

Caring Conversations. The Midwest Bioethics Center, based in Kansas City, Missouri, has developed a multimedia consumer education kit called *Caring Conversations*SM to foster conversations among family members while they are making practical preparations for end-of-life care decisions. The kit includes videotapes, printed materials, and slide presentations in a

comprehensive package of information and techniques designed to help people start talking about end-of-life issues with those who need to know.

The Midwest Bioethics Center is part of a national initiative to improve end-of-life care and recognizes that having the discussion about health care decisions is the first and perhaps only step many people will take in planning. Through the program's materials, people are encouraged to examine their wishes and communicate them clearly to family members.

Specifically, the Caring Conversations package seeks:

- To shift the focus of advance care planning to include conversations with family and friends
- To provide community education
- To educate health care providers who participate in advance care planning
- To help families become advocates for those who can no longer speak for themselves
- To ensure that the wishes of those near the end of life are honored.³

Means of addressing end-of-life issues.

Working with members of the community and the health care professions, the Oregon Health and Science University Center for Ethics in Health Care coordinated development of a form that many in that state find useful. The one page, two-sided form, Physician Orders for Life Sustaining Treatment (POLST) is designed to follow a patient across treatment settings. It is a medical order, signed by the patient's physician after discussion with the patient and family members. It enables patients to state their wishes on specific treatments. It is a standardized form used statewide, is printed on "shocking pink" paper, and is written in language that is clear, including the requirement to provide comfort measures. The POLST form is brief, simple, highly visible, portable, and carries authority. It focuses on comfort and serving the patient. Such a system might be developed in Michigan for improved decision-making (see www.ohsu.edu/ethics/polst.htm).

In 1999, two pilot projects in Midwestern states (Kansas and Wisconsin) began a replication of the POLST form. It was noted that Oregon spent five years in community and professional forums, creating consensus and the infrastructure needed to implement this form for statewide use. In the pilot areas, regional or county-wide use of the POLST form has been tested, with each site acknowledging that "without an infrastructure, POLST cannot succeed and could be misused."⁴

Other instruments are also available for addressing end-of-life issues beforehand and in writing.

Advance directives. This is a general term that refers to written documents that allow people to make known their wishes concerning health care options in case they become unable to participate in the decision making.

From the individual's point of view, achieving a sense of control and relieving the burden on family members are among key concerns at the end of life. In a survey of chronically ill people, more than a third indicated that they wanted a sense of control over the care they receive and the choices made about their care.⁵ Advance directives are one way to address those concerns, and can also be very helpful to families.

Researchers have reported that advance directives are very helpful to families of hospitalized patients at the end of life.⁶ Stress among families who were asked to decide about whether to continue life support for a hospitalized relative was considered in one study. Stress levels for those families without an advance directive to guide them were twice as high as stress due to other crises. Stress levels for those families with written directives were the lowest. With an advance directive, the family focused on the quality of life as the criterion for deciding when to stop life-sustaining treatments.

Living wills. Living wills were developed in 1967 in response to a newly identified medical outcome — the persistent vegetative state. In effect, the development of ventilators meant people no longer capable of breathing on their own could be kept alive. The cases of Karen Quinlan and Nancy Cruzan raised national awareness of the potential outcome of receiving breathing support or nutrition through technology. Central to each of these cases were two critical questions: did the incapacitated person have the right to have life support withdrawn, and is that what the person wanted? The Quinlan case established the right and means to have life support withdrawn from an incapacitated person. The Cruzan case addressed the importance of providing clear and convincing evidence of a patient's wishes to reject life support when the person was in a persistent vegetative state. Living wills grew in importance and popularity following these cases, as states and people sought legal mechanisms to assure that individual choices regarding life support would be allowed.

However, the American Bar Association says a living will is not the most effective document for directing health care decisions. Most living wills are limited in their scope and fail to address the complexities of health care. One common drawback is that living wills typically address only end-of-life care, rather than a full range of health care situations. In Michigan, living wills are not legally recognized, and while the document may be useful, it doesn't carry the same weight as the Durable Power of Attorney for Health Care document. As the Commission on Legal Problems of the Elderly points out, executing a living will can be useful if a person has no one to serve as a designated patient advocate or health care proxy, but it is not the best choice.

Durable Power of Attorney for Health Care. Michigan law recognizes this process, also known as the Designation of Patient Advocate, for expressing advance directives. After completing a document, a competent individual is allowed to name a patient advocate to make health care decisions when the person can no longer speak on his or her own behalf. The patient advocate designation covers not only end-of-life situations but also any situation in which the patient is unable to participate in health care decisions. The designation becomes effective when a person's physician and one other physician or licensed psychologist determine, based on an examination, that the person is unable to make medical treatment decisions.

One of the strengths of designating a patient advocate (also known as a proxy) is that the advocate has the power to act in the patient's interest and can respond to changing situations. Decision-making authority can be transferred during situations that are not necessarily terminal, and the proxy can make decisions based on the current available information. The reality of treatment decisions is often quite different than imagined. Technology and treatment options continue to expand, and advocates can make decisions based on their personal knowledge of the patient. It is important that the patient advocate be knowledgeable about the patient's wishes.

The Five Wishes. While Michigan provides a statutory form for the Durable Power of Attorney for Health Care, other documents that contain the same elements and meet the statutory requirements can be used as well. The Five Wishes is a form that allows an individual to specify who can make health care decisions as a proxy, the kind of medical treatment wanted or not, the type of comfort care desired, how people can provide support, and what loved ones should know. The Five Wishes, originally developed in Florida, has been revised with assistance from the American Bar Association and meets the legal requirements of 33 states, including Michigan, as an advance directive. Many people find the Five Wishes easier to understand than the Durable Power of Attorney for Health Care form; also, it includes personal wishes for spiritual or relationship matters.

My Voice, My Choice. The Oakwood Healthcare System in Southeastern Michigan developed an advance directive package to be used for completing a legally valid designation of patient advocate or durable power of attorney for health care. The package contains instructions, suggestions, a worksheet to help identify personal wishes, a booklet on various forms of medical treatments, the Durable Power of Attorney for Health Care form, and a wallet card. The Oakwood system has an instructional videotape that guides viewers through the package and answers common questions. One of the worksheets in the My Voice, My Choice kit asks the person making the decisions to indicate his wishes, then asks the designated proxy to answer the questions based on what he thinks the person wants. The amount of congruence or lack of agreement can be the basis for further discussion between the designator and the proxy.

Finally, it must be said that from the health care providers' perspective, remaining informed about and complying with advance directives represents a challenge. Patients are treated by a multitude of providers in hospitals, outpatient offices, and home settings. Various specialists have replaced the family physician, usually making a single conversation about end-of-life care impossible. People in hospitals face different staff by shift, rotation, and setting. The fragmentation of health systems creates barriers to continuity, even within a single building.

Surrogate decision-making.

All advance directives have an essential component in common: the person designating a proxy, completing the Durable Power of Attorney for Health Care form, or filling out a living will must be legally competent. If a person is not legally competent or if health care providers feel that a person is unable to understand the risk or consequences of a medical treatment well enough to give informed consent, the law requires a surrogate decision-maker.

Guardianship. This is the legal process by which a person is determined to be legally incompetent and the ability to exercise some or all civil rights is transferred to a court-appointed guardian. The extent of the guardian's powers is determined in court; however, guardians may be empowered to authorize health care, to determine where the ward resides, and to have control of the ward's finances.

Michigan revised its guardianship statutes effective January 1, 2001 (Michigan Public Acts 312-313 of 2000), amending the Estates and Protected Individuals Code to clarify questions regarding the simultaneous appointments of a patient advocate and a guardian. The law now states that if an individual has properly executed a patient advocate designation prior to being incapacitated,

the court cannot grant a guardian any of the powers held by the patient advocate. Conversely, a legally incapacitated individual who has a court-appointed guardian with responsibility for making medical treatment decisions cannot designate another individual as a patient advocate.

The law does allow for the court to intervene if a petition to modify a guardianship alleges that the patient advocate designation was not executed in compliance with the law, or that the patient advocate is not acting consistently with the ward's best interests. If the court finds the allegation to be true, the court may modify the terms for the guardianship to grant those powers to the guardian.

Further changes to the Estates and Protected Individuals Code became effective June 1, 2001, under a seven-bill package, Public Acts 463-469 of 2000. (Public Acts 312 and 313 of 2000 were unaffected.) One of the areas of change includes alternatives to full guardianship.

There are many alternatives to full guardianship for an individual who can no longer make decisions, including appointment of a limited guardian or conservator, patient advocate designation, do-not-resuscitate declaration, and durable power of attorney. To ensure that individuals are allowed the opportunity to choose the appropriate level of service, the law was changed to highlight these alternatives. To this end, a guardian *ad litem* (literally, during the litigation) will now report to the court regarding whether alternatives to full guardianship are advisable. A physician, mental health professional, or visitor who meets with the individual who is the subject of a petition shall inform the court on alternatives that may exist. When a person files for guardianship, he or she will receive information that includes a list of alternatives to the appointment of a full guardian.

Decision-making surrogate laws. Since it is estimated that 80 percent of adults do not have any written advance directives for end-of-life care, many complex situations result for families and health care providers when treatment decisions need to be made. Physicians often seek the family's views on treatment decisions; if they agree with the physician, often there is no need for further direction. However, family members may disagree with the physician or among themselves. Lacking the consensus and support of family members, physicians generally seek resolution outside the family, using a hospital ethics committees or even the court's rulings, for example.

Several states have enacted laws that address surrogate decision-making, creating a clear rank order of the class of family members who may be granted decision-making authority that is legally binding for health care professionals. Some states have adopted the Uniform Health Care Decisions Act, while others have enacted only portions of the act.

The Uniform Health Care Decisions Act aims to assist individuals and the health care professions to better assure a person's right to choose or reject a course of treatment. The act is designed to replace existing living will, power of attorney for health care and family health care consent statutes. The act, approved by the American Bar Association and American Association of Retired Persons (AARP), has been adopted in six states (Alabama, Delaware, Hawaii, Maine, Mississippi, and New Mexico). Other states did not adopt the uniform act but have established in statute the rank order of family members who can be granted surrogate decision-making powers for a person's health care.

The Uniform Health Care Decisions Act incorporates several aspects of end-of-life decision-making. It provides for the designation of a health care proxy, provides for personalized instructions for health care treatments, and allows the person to indicate wishes for organ donation at death. It also provides the option to designate a primary physician, an important factor when several doctors are involved in delivering health care.

The act also addresses the issue of surrogate decision-makers appointed in the absence of a specific designation. An order of priority is given to a list of groupings or classes of the patient's family, e.g., spouse, then adult children. Surrogates must be "reasonably available." The act recognizes that non-family relationships can be honored if family members are unavailable or decline the decision-making authority. It also provides for resolution when members of a deciding class, e.g., adult children, fail to agree on a health care decision, and it allows for disqualification of a class if the disagreement cannot be settled.

The act also addresses the issue of guardians' decisions, saying the guardian must comply with the ward's individual instructions and cannot revoke the ward's advance directive for health care unless the court approves. It also specifies that health care decisions by the designated proxy take precedence over those of the guardian.

Surrogate decision-making for persons who have never been competent. Some states have statutes that allow a surrogate to make a decision for an incompetent person. With regard to end-of-life care, enactment of such statutes requires a balance between assuring that individuals will not have to endure medically ineffective therapies or resuscitative measures, and protecting vulnerable persons who are not able to speak for themselves.

It is well recognized that courts have no particular expertise in health care decision-making. The Commission heard compelling testimony from one health care professional about the difficulties of the probate court's involvement in end-of-life decision-making. The guardian system currently allows guardians to have health care decision-making powers, but many guardians are receiving a stipend for their duties. Health care decisions that prolong the ward's life through life-sustaining measures can create the appearance of conflict of interest, especially in situations in which recovery is unlikely. Such situations can wind up weeks later in a courtroom, with a judge making the decision.

Summary.

Most experts agree that there are several areas that need to be discussed as part of end-of-life decision-making. One area is the designation of someone who can speak for the individual in deliberations about health care decisions. In Michigan the most effective method of assuring that the designation will be honored is to implement the Designation of Patient Advocate statute.

Another is establishing and understanding the medical treatments or care that the individual wants or does not want. These should be written into the designation. If the individual has specific wishes about resuscitation or being placed on life support equipment, these must be clearly stated, too, and should be as specific as possible for a variety of clinical conditions and prognoses. During a serious illness, physicians may raise some of these issues and note personal preferences in medical records.

Additionally, there are barriers to providing quality end-of-life care to those Michigan citizens who have never been competent.

Statistics indicate that most deaths in Michigan are not traumatic and sudden but the result of chronic illness. People should begin to think about end-of-life care when they are diagnosed with a serious illness; it is easier to think about these complex and often overwhelming issues before becoming seriously ill, as illness can create additional stress and discomfort. As an advocate for the aging said: People can choose to not decide ... but then they must accept that others may decide for them.

Each of us has an interest in assuring that all Michigan citizens have their wishes and choices for care met during their dying. The need for change is embodied in the recommendations that follow.

Recommendations.

The Final Report of the 1994 Michigan Commission on Death and Dying⁷ revealed that an aspect of death that Michigan citizens fear most is being kept alive by artificial means against their wishes. The fear was prevalent despite the fact that Michigan law unequivocally gives every competent adult the right to accept or refuse life-sustaining medical treatment. Under Michigan court cases, this right to make one's own decisions about medical treatment is not lost because a competent person becomes incompetent.⁸ This right, which is usually exercised by a surrogate, also exists for minors and other people who have never had legal capacity to make medical decisions.⁹

The Michigan Commission on End of Life Care makes the following recommendations for decision-making at the end of life.

1 Pertinent governmental and private agencies should launch a statewide medical decision-making awareness campaign. The campaign should be culturally sensitive, recognize the varying approaches to end-of-life care based on cultural beliefs and life experiences, and facilitate an understanding of the relationship between culturally informed practices and established principles of Michigan law. The campaign should encourage and provide guidance to all Michigan citizens to engage in caring conversations with their families and loved ones concerning their expectations and wishes for end-of-life care and should encourage citizens to designate a patient advocate¹⁰ or otherwise clearly document their wishes.

Rationale.

The testimony delivered at the Commission's public hearings indicated that there is confusion about the laws regarding medical decision-making and the legal mechanisms that can be used to preserve a person's wishes for medical treatment if a person becomes unable to make decisions. Many who testified recommended that a statewide awareness campaign be launched to educate people about the decision-making laws, as well as the differences among a designation of patient advocate, advance directives, living wills, powers of attorney, do-not-resuscitate orders, and other end-of-life decision-making tools.

A wide range of public and private agencies that serve the public should participate in the campaign, including government agencies, primary and secondary schools, institutions of higher education, churches, legal offices, bar associations, judicial training programs, health-profession organizations and associations, physician offices, health care systems, hospitals, managed care organizations, community and senior-citizen centers, and libraries.

Public testimony also underscored the need for understanding cultural beliefs as they relate to the end of life and for recognizing that the perspectives and approaches to end-of-life care vary depending on cultural beliefs and life experiences.

2 The Michigan Dignified Death Act¹¹ should be amended to provide that regardless of whether a patient is terminally ill, physicians should engage in discussions about medical directives during initial consultations, annual exams, in-hospital consultations at times of admission to or transfer from one health care setting to another, and at diagnosis of a chronic illness. One or more studies should be conducted to determine the best practices for involving physicians in effective discussions with patients about advance directives and actual implementation of advance directives. Managed care organizations, health plans, and other payors should be encouraged to include medical record documentation of physicians' discussions with patients as a quality indicator for physician practice.

Rationale.

As recommended in testimony given at the public hearings, the Commission encourages physician involvement in discussions with patients about advance directives. One concern was that while some conditions are not difficult to diagnose as a terminal illness, the diagnosis of others is not easy. In some conditions, a patient might die in any of a succession of medical crises that may occur over a period of months or even years; yet some patients survive these crises and live for many years. These patients need to have information about their rights to treatment alternatives and their rights in the event that a crisis results in serious medical complications.

Another frequently expressed concern was that even after diagnosing a terminal illness, many physicians fail to inform their patients about advance directives, pain management, and hospice care, as required by the Michigan Dignified Death Act. The public testimony further recommended that patient medical records include documentation of discussions between physicians and patients about advance directives and of the terms of any advance directive a patient signs. Witnesses also urged establishing a mechanism to ensure that health care providers follow existing advance directives. The POLST form, described above, is a way of increasing the prospect that patient advance directives will be noted and followed.

3 Information clearly denoting that a person has executed a do-not-resuscitate order should be added to the back of Michigan driver licenses or identification cards. The driver's license or other identification card should also specify when an individual has an advance directive and where it can be found.

Rationale.

Information on a driver's license or other identification card would enable a person's previously executed do-not-resuscitate order to be readily available at the scene of an

accident or emergency, or when a person is transported to a facility other than the one that has the person's medical records. In addition, information that an individual has an advance directive and where it can be found would be helpful for medical decision-making for a person who cannot personally make medical decisions.

4 The State Court Administrator's Office should take a leadership role in seeing that courts, court personnel, guardians *ad litem*, and others are well-prepared to administer and enforce the guardianship reform laws passed in 2000 and effective in 2001, and information about these laws should be included in professional education as well as the awareness campaign described in Recommendation 1.

Rationale.

The legislative history of the recent guardianship reform laws indicates an overuse of full guardianships.¹² This unnecessary plenary power was often given for medical treatment purposes or payment purposes for hospitals and nursing homes, even in cases when full guardianship was not necessary or beneficial for the ward.

The new guardianship laws require the courts to inform petitioners for guardianship of the many alternatives to full guardianships,¹³ including limited guardianship, conservatorship, powers of attorney, designation of patient advocate, and other advance directives. The goals of the guardianship reform laws are that a guardian's powers be limited to what is necessary to provide for the demonstrated need of the individual ward and that guardianships be designed to encourage the development of maximum self-reliance and independence for the individual.¹⁴ An individual who only needs assistance with finances should only have an attorney in fact under a power of attorney or a conservator and should retain authority over medical decision-making.

The Commission recognizes and supports the guardianship reform laws and encourages alternatives to guardianships in appropriate cases. The State Court Administrator's Office should see that all courts have the explanatory materials described in the law and that there are adequate educational opportunities for court personnel, the judiciary, and others who are frequently appointed as guardians *ad litem* or guardians. The existence of these alternatives to guardianship should be part of the awareness campaign recommended above.

5 The MDCH director should establish a working group of advocates, interested parties, and health care professionals to work toward assessing the numerous issues associated with end-of-life decision-making for persons in Michigan who have never been competent and who are terminally ill.

Rationale.

The Committee makes this recommendation in light of an opinion¹⁵ the Michigan Attorney General issued in 2000 regarding developmentally disabled people that states that a guardian cannot authorize withholding or withdrawing treatment in the absence of clear and convincing evidence of the ward's views expressed when competent. The Committee also is mindful of the Michigan case law in matters involving end-of-life care for formerly competent patients and for minors and other patients who have never been competent. The Committee agrees with the Michigan appellate courts that the case law in this complex area

should evolve over time in response to specific situations¹⁶ and agrees with the judicial philosophy that the overriding public policy of the state is to respect the roles of the patient, family, physicians, and spiritual advisers in medical decision-making and that courts should not intervene unless the parties directly concerned disagree about treatment or it is otherwise necessary to protect patients' interests.^{17,18}

The Estates and Protected Individuals Code (EPIC) incorporates the provisions of the former Michigan Designation of Patient Advocate statute¹⁹ and allows a competent adult to designate a family member or friend to make medical decisions in the event the adult becomes incompetent. Michigan law allows a guardian to authorize necessary medical treatment for a ward. Michigan has no statute that authorizes a guardian for a person who has never been competent and the numerous issues associated with end-of-life decision making for those persons.

The work group could obtain guidance for many types of difficult decisions by reviewing previous Michigan appellate court cases. One case acknowledges the right of a never-competent minor to have medical treatment withdrawn under certain circumstances. The analysis in that case is applicable to a wide range of difficult medical decisions involving minors.²⁰ Another appellate court case recognizes a process for making end-of-life decisions for other people who were formerly competent.²¹

The Michigan Attorney General's ruling in 2000 has caused certain guardians to be apprehensive of their powers in similar cases. The opinion, which was designed to protect the vulnerable developmentally disabled population from neglect, also has had the unintended consequence of subjecting developmentally disabled people (and possibly others) whose death is anticipated from an advanced severe illness to undergo medically ineffective therapies and painful resuscitative measures as they are dying.

Thirty-two states have some legal mechanism that allows a surrogate to make a decision for an incompetent person. While Michigan has certain statutes of this type, it has no statute that addresses the rights of guardians for developmentally disabled people. Moreover, the court cases do not clarify the situation for those persons who have never been legally competent.

The Committee recognizes the need to have safeguards to protect vulnerable, incompetent individuals who do not necessarily have guardians who represent their best interests. This recommendation could encourage a work group to:

- Consider the issue of surrogate end-of-life decision-making by a patient's guardian, available for people with developmental disabilities who have advanced, severe illness that is expected to cause death imminently or within a few months. They should also review a variety of circumstances for which law changes are appropriate, including if:
 - The treating physician has certified the nature of the patient's medical condition; the diagnosis and prognosis; and the nature of the treatment involved, the consequences, benefits, risks and burdens of the treatment and of non-treatment.
 - A second physician in the applicable medical specialty confirmed the treating physician's certification.
 - The certification and confirmation were recorded in the patient's medical record before a surrogate's end-of-life medical decision could be implemented. There could

- be prior notification to the patient's next of kin, significant others, and anyone else who expressed an interest in the patient's welfare.
- Review policy implications in circumstances when there are objections to the surrogate's end-of-life decision by any family member or other person, these potential components of any law changes could include:
 - An institutional biomedical ethics committee or subcommittee of a biomedical ethics committee could be consulted for review of the medical decision if the patient is in a medical facility or resides in another facility that has a biomedical ethics committee. The review could determine whether the medical decision was in the patient's best interest. The biomedical ethics committee or subcommittee could include people with expertise in biomedical ethics, one or more members of the public, and people knowledgeable about the patient's cultural and religious or spiritual background and could include people from other disciplines such as medicine, nursing, social work, psychology, religion, and law. Employees of the facility in which the patient is located would not constitute a majority of those on the committee or subcommittee.
 - If the patient were not in a facility or if the facility did not have a biomedical ethics committee, a judicial review could be conducted to determine if the medical decision was in the best interest of the patient.
 - Advance notification of the biomedical ethics committee or subcommittee deliberations or judicial hearing would need to be given to next of kin and all other interested parties. They could be invited to participate and to provide information about the patient's cultural, religious, or spiritual background.

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7. Created pursuant to Michigan Consolidated Laws (MCL) Section 752.1023.
8. In re Martin, 450 Mich 204 (1995).
9. In re Rosebush, 195 Mich App 675 (1992).
10. MCL Section 700.5506 et seq.
11. MCL Section 333.5651 et seq.
12. House Fiscal Analysis for House Bills 5919 and 5921 (Oct. 5, 2000), and House Legislative Analysis Section, Senate Bills 863 and 1385-1390 (Dec. 5, 2000).
13. MCL Section 700.5303.
14. MCL Section 700.5306
15. 2000 Office of the Attorney General, Opinion No. 7056; see www.ag.state.mi.us/opinion/datafiles/2000s/op10126.htm
16. In re Martin, 450 Mich at 223.
17. In re Rosebush, 195 Mich App at 687.
18. National Center for State Courts, *Guidelines for State Court Decision Making* (Williamsburg, Va., 1991), p. 101-122.
19. These provisions were previously found at MCL Section 700.496 and are now found at MCL section 700.5506 et seq.
20. In re Rosebush (see note 9 above).
21. In re Martin (see note 8 above).

V(F). Family issues.

Compassionate, effective care at the end of life requires attention to the psychological, social, and spiritual dimensions of the patient's experience as well as to physical symptoms. To attend to this broader sense of what it means to be a whole human person facing death requires an integrated approach that draws on the perspectives and skills of an interdisciplinary team of caregivers. Such an approach will acknowledge the patient's psychological and cognitive experience of illness and death and the role of social relationships and support, as well as the spiritual and existential beliefs that may contribute to a sense of meaning and purpose at the end of life. It will account for the needs of caregivers while they are caring for the dying — and for the grief and bereavement that accompanies and follows the death of a loved one.

An integrated approach.

Efforts to understand and evaluate quality of care at the end of life, from the early insights of Saunders¹ and Kubler-Ross² to more recent work such as the Commonwealth Fund-Nathan Cummings Foundation Project on the End of Life, have led to an evolving understanding of dying as a multi-dimensional experience. Emanuel and Emanuel³ usefully synthesize the experience of dying as a process with four critical components:

- The fixed characteristics of the patient. These include elements that will not change over the course of the dying process such as disease, prognosis, and socio-demographic characteristics of age, gender, and ethnicity.
- The modifiable dimensions of the patient's experience, elements that may respond to events or interventions. These include physical symptoms such as pain, which are treatable by medical interventions, but they also include psychological and cognitive symptoms such as depression, anxiety, or confusion. They include social relationships and support from family and community. Economic demands and caregiving needs include the effect of the patient's illness and dying on their needs for personal care and nursing care, and their ability to pay for such care. The hopes and expectations of the dying person may also be subject to change over the course of the dying process, including the ways in which milestones are marked and how patients assess and view their own prognosis. Finally, the patient's spiritual and existential beliefs, whatever their source or the language and symbols in which they are expressed, are often a source to help make sense of the dying experience, to seek a sense of purpose and meaning and peace at the last.
- The third component in this model addresses the potential interventions available to family, friends, health care providers, and others. For family and friends, such interventions might include opportunities for communication about important issues in relationships, or meeting caregiving needs. Social interventions might include providing spiritual support through individual pastoral care professionals, religious or spiritual leaders, or spiritual communities such as religious congregations. Medical interventions must include effective communication with the patient and family about important decisions such as advance care planning. Health care system interventions might include the provision of pain-relief services, comprehensive palliative care services, hospice care, or home care services.
- Finally, the interventions available from social institutions such as insurance coverage, employee benefits, or government programs contribute to the availability and accessibility of other interventions.

Such a framework for understanding the dying experience can contribute to more effective and compassionate care of the dying. It emphasizes the multifaceted character of the experience of dying patients, broadening our focus beyond considerations of physical symptoms to include psychological well-being, economic demands, caregiving needs, social relationships, hopes and expectations, and spiritual and existential beliefs.

It is important to note that each of these dimensions includes a range of concerns that are interconnected with others. Many physical symptoms have psychological components, for example. A patient who is depressed or experiencing a sense of existential meaninglessness may have a lower pain threshold, while patients who report spiritual fulfillment or good social support may be less bothered by their physical symptoms. A comprehensive view of the dying process contributes to a comprehensive, interdisciplinary plan of care for the dying.

In one Michigan community, the Traverse Area Coalition for Dignity at the End of Life has been formed as a community health partnership with more than 100 members (individuals and organizations). The coalition has used a discussion-based format to evaluate the communities' wishes for end-of-life care and to promote advance care planning. The group sent out 2,500 surveys to evaluate the above; 732 were used for data analysis. They found that the community believes that:

- Dying is less a medical event than a family one (95 percent want care by family).
- Most prefer to die at home (69 percent) or in a hospice residence (22 percent).
- Seventy percent want hospice services when dying, but hospice care reaches only 13 percent of their community.

The coalition also identified four groups with unique and specific roles in support for those at life's end. These were family, the faith community, health care providers, and neighbors. The types of support valued from each of these groups was identified in the survey report.

As central as health care providers are to the care of dying patients, an integrated view will avoid seeing dying as solely a medical experience and will acknowledge the role of the patient's whole social network in the caregiving process. Moreover, while focusing on the whole range of needs of the dying patient, it is critical to acknowledge the roles — and needs — of others, from family and friends to religious congregations and community support groups.

Support for caregivers.

If effective and compassionate care at the end of life is seen as a plan of care rather than a specific medical treatment, then part of that plan will include attending to the needs of families and caregivers of the dying. The emotional, physical, and financial demands on family members who care for a dying loved one at home must be taken into account in developing and coordinating the plan of care.

Support may come from physicians who coordinate the plan of care and remain in close contact with the family and with members of the palliative care or hospice team of caregivers. It may also come from hospice and palliative care nurses who help to monitor the patient's condition, provide the family with information about the illness, and help them manage the pain and symptoms of the disease. A social worker might act as a counselor to the patient and family,

helping them deal with financial, legal, and insurance issues; the social worker might also help the family cope with the personal and social challenges of disease, disability, and the dying process. A spiritual counselor might work closely with the hospice or palliative care team to attend to the unique needs of each individual for spiritual support, as well as support from any faith community or congregation of which the patient may be a part. A religious or spiritual community might be one important source of both spiritual and social support and solace for many families as they cope with the illness and the demands of caregiving.

Others involved in the care of the dying patient who might also help support the family's caregiving needs, include home health aides, therapists, volunteers, and bereavement counselors as well as extended networks of relatives, neighbors, and friends.

Respite care, in which caregivers have the opportunity to take a break from the rigors and demands of constant physical care of the dying, is an important part of the care plan for many families. Respite care is both skilled and unskilled; it can be provided in an acute-care hospital, a hospice residence, by home care or hospice personnel in the patient's home, or in locations specifically designed to provide respite services. Some of these sites require staff who have specific education and skills in symptom management for the dying so that the primary caregiver can have peace of mind as well as respite from duties. Such skilled personnel are highly sought, and improved reimbursement streams will need to grow to fill this unmet health care manpower need. Data suggest that the physical and emotional health of the survivor are affected by the adequate provision of respite care, and negatively affected by lack of respite care. Respite care support may be provided informally through a congregation or by friends or other family members, or it may take the form of organized respite care programs in communities, which help provide much-needed care to the caregivers of the dying.

In addition to respite care programs offered by hospice programs throughout Michigan, community-based programs such as the Capital Area Interfaith Respite Program (CAIR) also provide respite services. CAIR recruits, trains, and supervises volunteers who provide temporary relief for two to four hours a week to caregivers of homebound, chronically ill, or handicapped adults free and without physician or agency referral.

Bereavement support.

Hospice and palliative care programs should be designed to address all the issues of a terminal illness, including patients' and families' needs during illness, and survivors' needs for support as they proceed through the grieving process. After the death of a loved one, it is natural to experience sadness, loss, and grief; many people feel also anger and loss of control. While grief is certainly an emotional experience, it is also a physical, social, and spiritual experience. All these elements of bereavement need to be addressed in effective end-of-life care.

Bereavement programs are available through hospice programs and other community resources. In the year following death, it is vital for hospice programs to follow up with the primary caregivers or family members who have experienced the death of a loved one, whether through bereavement counseling services or through grief support groups. Many survivors join grief support groups even if they were not involved in hospice care. It is often important to dying patients to know that their families will be cared for after their death, and providing this support is an important way of offering care and compassion to both patients and their loved ones.

The education of health professionals needs to include the psychological, social, and spiritual support needed by patients and their families. This education can be provided in professional schools, postgraduate education, and continuing education, or it may come from specialized instruction such as the program on grief and bereavement available in Madonna University's hospice care education program. Many funeral homes also provide bereavement services or counselors. Community support groups, faith communities, and the human resource departments of some businesses may also provide information or services.

The needs of grieving children can be addressed by programs such as Ele's Place in Lansing, a not-for-profit community-based organization that provides support group services to children and youth (from ages 3 to 18) as well as young adults (from 19 to 26) and their families who have experienced the death of a loved one.

Cultural factors.

Recognizing the role of culture in end-of-life care helps account for the ways in which all people live in relationship to the group or groups with whom they identify. An individual's cultural identity may be based on heritage as well as individual characteristics, circumstances, and personal choices. Cultural identity is affected by such factors as race, ethnicity, age, language, country of origin, acculturation, sexual orientation, gender, socioeconomic status, religious or spiritual beliefs, physical abilities, and occupation, among others. These factors may affect behaviors related to end-of-life decisions, including communication styles, diet, health beliefs, family roles, lifestyle, rituals, and decision-making processes. All these beliefs and practices, in turn, can influence how patients and health care professionals perceive health and illness and how they interact with each other.

One model for how to take culture effectively into account in developing and implementing a plan of care is the Transcultural Consultation Service at Oakwood Health System in Dearborn. This service provides system-wide support in effective, culturally sensitive communication for patients and health care providers. More than translation, culturally sensitive interpretation of health care information is particularly important to families and patients in the process of making informed decisions about care at the end of life. Such interpretation takes into account not just differences in language but also the cultural values that are important to patients and that profoundly influence their choices in end-of-life care.⁴

Recommendations.

The Commission makes these recommendations for improving the delivery of effective, compassionate, and comprehensive end-of-life care and related services to patients, families, and loved ones in Michigan.

1 Because the health, finances, and well-being of family members are often threatened as they care for the dying and because family members require support to ensure the successful completion of life tasks, the Michigan Department of Community Health, the Michigan Department of Consumer and Industry Services, and other organizations as appropriate should undertake to evaluate these and other family-related issues in order to understand better the circumstances of Michigan families and to focus development of programs to aid them.

2 To deliver effective and compassionate care at the end of life, Michigan health care providers, including those in the social, psychological, and pastoral care disciplines, need to acquire, in the course of their professional and post-professional education:

- a) An understanding that death is a natural part of life, that suffering and loss are an integral part of the human life cycle, and that the role of the health care provider includes the comprehensive care of the patient and the patient's family during the entire transition from life to death.
- b) The skills necessary to deliver difficult news about end-of-life issues to patients and their families in a caring and compassionate manner, to elicit patients' values, beliefs, and preferences for treatment at the end of life, and to obtain advance directives and knowledge of surrogacy issues
- c) The ability to recognize the spectrum of physical, emotional, sociocultural, and spiritual symptoms of distress that patients may exhibit at the end of life and to formulate appropriate responses to them.
- d) The ability to work with and value a multi-disciplinary team approach to delivering end-of-life care and to communicate effectively with other providers of care in order to deliver appropriate care to patients at the end of life.
- e) An understanding that the concept of palliative care refers to all the dimensions of care (physical, psychological, social, and spiritual) that should be provided at the end of life.

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Web sites.

Agency for Healthcare Research and Quality (for clinical practice guidelines for managing pain):

<http://www.ahrq.gov>

American Academy of Hospice and Palliative Medicine:

<http://www.aahpm.org>

American Academy of Pain Medicine:

<http://www.painmed.org>

British Medical Journal: Pain:

www.bmj.com/cgi/collection/pain

Center to Improve Care of the Dying:

www.medicaring.org

Growth House, Inc.:

www.growthhouse.org

History of Pain Collection (University of California at Los Angeles History of Pain Project):

www.library.ucla.edu/libraries/biomed/his/pain.htm

Innovations in End of Life Care (journal):

www.edc.org/lastacts

Institute for Healthcare Improvement:

www.ihp.org

Medscape Resource Center: Pain Management:

neurology.medscape.com/Medscape/features/ResourceCenter/pain/public/RC-index-pain.html

Merck Manual of Diagnosis and Therapy — Neurologic Disorders — Pain.

www.merck.com/pubs/mmanual/section14/chapter167/167a.htm

Pain.com:

www.pain.com/cme/default.cfm

Promoting Excellence in End of Life Care (a national program of the Robert Wood Johnson Foundation):

www.promotingexcellence.org

Supportive Care of the Dying:

www.careofdying.org

10 characteristics of pain:

www.medscape.com/Medscape/features/pearls/2000/03.00/cp-0302pain.html

University of Iowa College of Nursing-International Center for the Control of Pain in Children and

Adults: www.nursing.uiowa.edu/sites/PedsPain/

University of Wisconsin Comprehensive Cancer Center, Pain and Policy Studies Group:

<http://www.medsch.wisc.edu/painpolicy>

VII. Glossary.

- Acupuncture.** A procedure in which specific body areas associated with peripheral nerves are pierced with fine needles to produce anesthesia, relieve pain, and promote therapy.
- Addiction.** Addiction is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. Drug addiction is characterized by behaviors that include one or more of the following: impaired control of drug use, compulsive drug use, continued drug use despite harm, and craving for drugs.
- Adjuvant analgesic drug.** A drug that is not a primary analgesic but a medication that research has shown to have independent or additive analgesic properties (e.g., antidepressant or anticonvulsant).
- Advance directive.** A statement made by a competent individual about his or her preferences for health care treatment in the event he or she becomes unable to make decisions. Often used to describe the two forms that many states recognize as legally important—the living will and the durable power of attorney for health care (health care proxy).
- Advanced illness.** Cancer of the colon, liver, pancreas, trachea, bronchus and lung, or melanoma, esophagus, breast metastasis, prostate metastasis, leukemia, or Hodgkin’s disease; congestive heart failure or chronic obstructive pulmonary disease for which the person has had two or more hospitalizations or one or more hospital admissions into the intensive care unit within the last six months.
- Adverse effect.** A negative medical consequence from use of an appropriately prescribed medication. The adverse effect may be inadvertent, known, or anticipated or idiopathic or of unknown cause.
- ARCOS.** Automation of Reports and Consolidated Orders System. An automated, comprehensive drug reporting system that monitors the flow of the United States Department of Justice Drug Enforcement Agency-controlled substances from their points of manufacture through commercial distribution channels to points of sale or distribution: hospitals, retail pharmacies, practitioners, mid-level practitioners, and teaching institutions. The list of controlled substance transactions tracked by ARCOS includes all Schedule I and Schedule II (see below) materials (manufacturers and distributors); and selected Schedule III and Schedule IV psychotropic drugs (manufacturers only).
- Cardiopulmonary resuscitation (CPR).** A technique of breathing for and applying chest compressions to a person whose breathing and heart have stopped.
- Caregiver.** Someone who is responsible for attending to the needs of an ill person. An informal caregiver is non-paid, usually a member of the family or a friend; a formal caregiver is paid and is someone with education in the field or recognized instruction.
- Chilling effect.** Reluctance by physicians (or other prescribers) to prescribe an adequate level of Schedule II drugs to control acute levels of pain. Causes of this effect often cited include programmatic structures (such as in Michigan’s OPP) that require the use of special prescription forms, or fears by licensees of regulatory audits by government that could result in sanctions against them.
- Chronic pain.** See Pain.
- Combination therapy.** A method of treating disease through the simultaneous use of a variety of drugs and other therapies to eliminate or control the biochemical cause of the disease.
- Comfort care.** Emphasizes that the goal of treatment is pain management, support, and relief from suffering, rather than cure.
- CSA.** Controlled Substances Act. A federal law, formally called Title II of the Comprehensive Drug Abuse Prevention and Control Act of 1970 and 21 United States Code, which consolidated various laws regulating the manufacture and distribution of narcotics, stimulants, depressants, hallucinogens, anabolic steroids, and chemicals used in the illicit production of controlled substances. See www.usdoj.gov/dea/concern/abuse/chap1/contents.htm

DAWN. Drug Abuse Warning Network. A federal program that uses medical records to monitor national drug abuse trends and adverse health effects, as well as adverse effects of appropriately prescribed medications.

DEA. Drug Enforcement Administration, an agency within the U.S. Department of Justice.

Diversions. In the context of prescription drugs and controlled substances that have legitimate, medically recognized uses to relieve pain and suffering, the act of using or distribution of a substance for other than its stated intent.

Doctor-shopper. A person perceived as visiting from physician to physician in order to get certain medications prescribed.

Do-not-resuscitate (DNR) order. A physician's or individual's explicit written instructions to health care providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. In Michigan, may be supplemented with a bracelet worn by the person for whom the order is intended.

Drug. Any chemical compound that may be used on or administered to humans or animals as an aid in the diagnosis, treatment or prevention of disease or other abnormal condition, for the relief of pain or suffering, or to control or improve any physiologic condition.

Drug abuse. The non-medical use of a substance for psychotropic effect, dependency, or suicide attempt or gestures. Can involve the use of illicit drugs, prescription drugs used in a manner that is inconsistent with accepted medical practice, and over-the-counter drugs used in a manner contrary to approved labeling.

Durable power of attorney for health care. Also known as the Designation of Patient Advocate, this allows an individual to name a person, called the patient advocate, to make health care decisions when the individual can no longer speak on his or her own behalf. The patient advocate designation covers not only end-of-life situations, but also any situation in which the patient is unable to participate in health care decisions. The designation becomes effective when a person's physician and one other physician or licensed psychologist determine, based on an examination, that the person is unable to make medical treatment decisions.

Guardian *ad litem*. Guardian during litigation. A person appointed to represent the individual during a court proceeding of some sort, for example, deciding if someone needs a guardian, what the powers of a guardian should be, whether a guardian should be removed, or whether someone should be involuntarily committed to a mental hospital.

Family. In the context of "patients and their families," this term is used in the broadest sense to include legal relatives, spouses, life partners, unrelated friends, and caregivers, all of whom care about the patient.

Hospice care. A type or model of care provided to a terminally ill patient that uses an interdisciplinary or team-oriented approach of expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's wishes. Hospice care focuses on enhancing the dying person's quality of life rather than trying to cure the illness. Hospice care can be provided in a home, hospital, nursing home, or licensed hospice residence.

Illegal drug. Any drug listed on the Michigan Controlled Substances Chart of the Michigan Public Health Code (Michigan Combined Laws 333.1101 et seq., Public Acts 368 of 1978), such as cocaine, heroin and marijuana. Exempted are any drugs on the list, such as codeine or morphine, for which someone has a valid prescription.

Living will. A document stating an individual's instructions for treatment to be used when that person becomes unable to express his or her wishes for health care treatment.

Narcotic. A word commonly used to describe morphine-like drugs and other drugs of abuse. Derived from the Greek term *narke*, meaning numbness or torpor. Usually an imprecise and pejorative term, so its use with reference to opioids is discouraged.

- Opioid.** A morphine-like medication that produces pain relief; refers to natural, semi-synthetic, and synthetic drugs that relieve pain by binding to opioid receptors in the nervous system. The term “opioid” is preferred to “opiate” because it includes all agonists and antagonists with morphine-like activity, as well as naturally occurring and synthetic opioid peptides.
- Pain.** A multi-dimensional, unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.
- Pain, acute.** Pain that has a sudden onset and commonly declines over a short time (days, hours, minutes). Follows injury to the body and generally disappears when the bodily injury heals.
- Pain, chronic.** Pain that lasts more than six months.
- Pain, chronic (non-malignant).** Pain or discomfort that has lasted for a long time, such as six months or longer, is ongoing, is due to non-life-threatening causes, and may continue for the remainder of the person’s life.
- Pain, neuropathic.** Pain that results from a disturbance of function or pathologic change in a nerve.
- Pain, nociceptive.** Pain that results from actual or potential tissue damage.
- Palliative care.** Palliative care refers to a comprehensive management of the physical, psychological, social, spiritual and existential needs of patients. Palliative care seeks to relieve the suffering of terminally ill patients and their families and can be complementary to other therapies.
- Patient advocate, designated.** As allowed by the Designation of Patient Advocate statute, a person named by another individual to make health care decisions when the latter can no longer speak on his or her own behalf. This designation covers not only end-of-life situations, but also any situation in which the patient is unable to participate in health care decisions. The designation becomes effective when a person’s physician and one other physician or licensed psychologist determine, based on an examination, that the person is unable to make medical treatment decisions. (See also Durable power of attorney for health care).
- Peer review.** Evaluation of a guideline by an interdisciplinary panel of experts using the Institute of Medicine attributes of clinical practice guidelines as evaluation criteria.
- Physical dependence.** A state of adaptation that is manifested by a drug class-specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist.
- Physical modalities.** Use of physical methods such as heat, cold, massage, or exercise, to relieve pain.
- Pseudoaddiction.** Pattern of drug-seeking behavior of patients receiving inadequate pain management that can be mistaken for addiction.
- Regulatory complaint.** A mechanism that allows consumers to file with state licensing agencies their criticisms or objections to procedures or care provided by licensed health care providers (such as physicians, nurses, dentists, or pharmacists) or licensed health care institutions or systems (such as nursing homes, home health agencies, hospice facilities, hospitals, freestanding surgical units, ambulatory surgical units, or end-stage renal dialysis centers). The agency receives and processes such complaints by following specific guidelines and processes established by statute or rules.
- Respite care.** Temporary care provided by someone else so that the everyday caregiver can have a break or attend to other responsibilities.
- Schedule I drugs** (includes heroin, LSD, and marijuana) have these characteristics: (A) The drug or other substance has a high potential for abuse. (B) The drug or other substance has no currently accepted medical use in treatment in the United States. (C) There is a lack of accepted safety for the use of the drug or other substance under medical supervision.

Schedule II drugs (includes Marinol, methadone, morphine, methamphetamine, and cocaine) have these characteristics: (A) The drug or other substance has a high potential for abuse. (B) The drug or other substance has a currently accepted medical use in treatment in the United States or a currently accepted medical use with severe restrictions. (C) Abuse of the drug or other substances may lead to severe psychological or physical dependence.

Schedule III drugs (includes anabolic steroids) have these characteristics: (A) The drug or other substance has a potential of abuse less than the drugs or other substances in Schedules I and II. (B) The drug or other substance has a currently accepted medical use in treatment in the United States. (C) Abuse of the drug or other substance may lead to moderate or low physical dependence or high psychological dependence.

Schedule IV drugs (includes Valium and other tranquilizers) have these characteristics: (A) The drug or other substance has a low potential for abuse relative to the drugs or other substances in Schedule III. (B) The drug or other substance has a currently accepted medical use in treatment in the United States. (C) Abuse of the drug or other substance may lead to limited physical dependence or psychological dependence relative to the drugs or other substances in Schedule III.

Schedule V drugs (includes codeine-containing analgesics) have these characteristics: (A) The drug or other substance has a low potential for abuse relative to the drugs or other substances in Schedule IV. (B) The drug or other substance has a currently accepted medical use in treatment in the United States. (C) Abuse of the drug or other substance may lead to limited physical dependence or psychological dependence relative to the drugs or other substances in Schedule IV.

Terminal illness. Advanced illness that no longer responds to curative interventions and has a limited prognosis; usually meant as leading to death.

Titration. Adjusting the amount (e.g., adjusting the dose of a drug such as an opioid).

Titration to relief. A gradual increase in pain medication until the highest pain relief is obtained, making the pain as tolerable as possible while minimizing short- and long-term effects.

Tolerance. A state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time.

VIII. Appendices

- A. Executive orders.
- B. Public hearings.
- C. Barriers to end-of-life care.
- D. Survey instruments used by Commission work groups.
- E . Insurance survey report.

EXECUTIVE ORDER No. 1999 – 4

MICHIGAN COMMISSION ON END OF LIFE CARE**MICHIGAN DEPARTMENT OF COMMUNITY HEALTH**

WHEREAS, the citizens of Michigan endorse humane and dignified treatment during life and at the end of life. Ninety percent of all citizens will experience a terminal phase of disease prior to death; and

WHEREAS, physician-assisted suicide raises moral and ethical questions for physicians, policy-makers, patients and their families; and

WHEREAS, last November, Michigan voters were offered the choice of whether or not the state should decriminalize the practice of physician-assisted suicide and voted overwhelmingly to reject such a plan; and

WHEREAS, although many laws to address end of life issues exist and ensure individual autonomy in health care decisions, the individuals are often unaware of their right to make decisions to receive, continue, discontinue or refuse medical treatment; and

WHEREAS, the subject of appropriate pain management practices has long been a concern of patients, medical practitioners, regulatory boards and state legislators. The whole spectacle of assisted suicide has made treatment of intractable pain a significant societal issue; and

WHEREAS, research indicates that barriers exist to adequate and appropriate use of prescription drugs for pain management and for the provision of end of life care; and

WHEREAS, the quality of end of life care is dependent in part upon the quality of the education and training of present and future physicians, nurses, and other health care professionals. The undergraduate, graduate and continuing education, including residency training, for physicians, nurses, and other health professionals plays a critical role in preparing care providers to deliver high quality end of life care; and

WHEREAS, the public and many private organizations including, but not limited to, health professional organizations, religious organizations, and trade associations have established committees and working groups to study and recommend actions to improve the quality of end of life care. The opinions and recommendations of these organizations and the public are considered of great value.

NOW, THEREFORE, I, John Engler, Governor of the state of Michigan, pursuant to the powers vested in me by the Constitution of the state of Michigan of 1963 and the laws of the state of Michigan, do hereby order the following:

A. Establishment of the Michigan Commission on End of Life Care

1. The Michigan Commission on End of Life Care ("Commission") is established by this Executive Order in the Michigan Department of Community Health ("Department").
2. The Commission shall consist of 17 members to be appointed by the Governor. The Commission shall serve at the pleasure of the Governor. The Governor shall designate one (1) member of the Commission to serve as its chair and who shall serve as chair at the pleasure of the Governor. Members of the Commission shall attend Commission meetings in person, and shall not delegate their responsibilities to other persons.

B. Charge to the Commission:

1. The Commission shall, by whatever means the Commission deems appropriate, identify, compile and consider recommendations for improving end of life care from the public and private organizations throughout Michigan.
2. The Commission shall recommend model state and institutional policies with respect to end of life care, including an examination and compilation of the best ideas of multiple groups currently engaged in examining end of life issues and shall consider these in the development of the Commission's final report.
3. The Commission shall coordinate their efforts with other groups actively engaged in addressing end of life issues, including but not limited to, the Circle of Life Committee in the Department of Community Health and the Advisory Committee on Pain and Symptom Management in the Michigan Department of Consumer and Industry Services.
4. The Commission shall identify and evaluate any existing barriers that result in inadequate end of life care in Michigan and, where appropriate, make recommendations for elimination or mitigation of such barriers.
5. The Commission shall evaluate the adequacy of education associated with end of life care being provided in Michigan schools of medicine, Michigan schools of nursing and in other health professional education programs and, where appropriate, make recommendations to improve such education.
6. The Commission shall evaluate the adequacy of the level and degree of graduate medical education being provided in Michigan residency programs associated with end of life care and, where appropriate, make recommendations for changes to improve such graduate medical education training.
7. The Commission shall survey availability and cost of public and private insurance coverage for hospice, pain management, and palliative care.

8. The Commission shall recommend, where appropriate, state policies concerning end of life care related to continuing medical education for health professionals licensed in Michigan.
9. The Commission shall inventory existing resources available to citizens for end of life planning and produce a guide of these resources for the general public.

C. Work Products

The Commission shall produce the following work products:

1. No later than Fifteen (15) months after the effective date of this Executive Order, the Commission shall issue a final report to the Governor and the legislature containing its recommended model state and institutional policies and the rationale of the Commission supporting their adoption.
2. The results of the Commission's survey on the availability and cost of public and private insurance coverage for hospice, pain management, and palliative care.
3. An inventory of existing resources available to Michigan citizens for end of life planning, published in the form of a Resource Guide for distribution to the general public.

D. Operations of the Commission:

1. Members of the Commission shall serve without compensation. Members of the Commission may receive reimbursement for necessary travel and expenses according to relevant procedures of the Civil Service Commission and the Department of Management and Budget.
2. The Commission may adopt rules of procedure, not inconsistent with Michigan law and with this Executive Order, governing its organization and operations. A majority of the serving members constitutes a quorum for the transaction of business at a meeting, notwithstanding the existence of one (1) or more vacancies. Voting upon actions taken by the Commission shall be conducted by a majority vote of the members present in person at a meeting of the Commission.
3. The Commission shall meet at the call of the chair and as may be provided in the rules of procedure of the Commission. Meetings of the Commission may be held anywhere within the state of Michigan.
4. The Commission shall establish one or more work groups to investigate and analyze specific issues, consistent with the charge of the Commission, concerning end of life care. The chair of the Commission, or a member of the Commission designated by the chair, shall be an ex officio member of each work group established by the Commission. Work groups shall recommend proposed state statutory, institutional or administrative policies to the Commission, consistent with the Commission's charge. The Commission may adopt, reject, or modify policies proposed by work groups for inclusion in its final report to the Governor and the legislature.

5. The Commission may apply for, receive, and expend monies from any source, public or private, including but not limited to gifts, grants, donations of monies and government appropriations. The Commission may also accept donations of labor, services, or other things of value from any public or private agency or person. The Commission may expend monies for its operations and contract for the services of such staff, agents, and consultants as it deems necessary to fulfill its responsibilities.
6. Prior to the first meeting of the Commission, the chair of the Commission shall notify members of the time and location of the first meeting of the Commission, establish the agenda for the first meeting, provide members of the Commission with any preparatory materials for the first meeting and make any other arrangements necessary for the start-up of the Commission.
7. The Department, or a non-profit corporation established by the Department pursuant to Act No. 264 of the Public Acts of 1989, shall provide management-related functions to the Commission including, but not limited to, contract management, personnel, accounting, and procurement services.
8. The Chairperson of the Commission shall regularly report on the Commission's progress to the Governor or his designee.

E. Miscellaneous Provisions

1. All departments, boards, commissions or officers of the state or of any political subdivision of the state shall give to the Commission, or to any member or agent thereof, any necessary assistance required by the Commission, or any agent of the Commission, in the performance of the duties of the Commission so far as is compatible with its, his or her duties; free access shall also be given to any books, records or documents in its, his or her custody, relating to matters within the scope of the inquiry, study or investigation of the Commission.
2. The Chairperson of the Commission, or his or her designee, including but not limited to, a work group established by the Commission, and any staff, agents, or consultants to the Commission, shall make themselves available to testify before the legislature, as necessary, to effect the enactment of the Commission's recommended policies into law.
3. Members of the Commission shall refer all legislative and media contacts to the Department.
The provisions of this Executive Order shall become effective upon filing.

Given under my hand and the Great Seal of the state of Michigan this 11th day of June, in the Year of our Lord, One Thousand Nine Hundred Ninety-Nine.

(signed) **John Engler**

GOVERNOR

EXECUTIVE ORDER No. 2000-2

MICHIGAN COMMISSION ON END OF LIFE CARE**MICHIGAN DEPARTMENT OF COMMUNITY HEALTH**

WHEREAS, Article V, Section 1, of the Constitution of the state of Michigan of 1963 vests the executive power in the Governor; and

WHEREAS, on June 11, 1999, The Michigan Commission on End of Life Care ("Commission") was established by Executive Order 1999-4; and

WHEREAS, the awarding of a major grant from the Robert Wood Johnson Foundation to research and advance end of life care in Michigan presents the opportunity to achieve great synergy with the mission of the Commission for the benefit of Michigan citizens; and

WHEREAS, the parallel purposes of the grant and the Commission's goals can best be achieved by changing the reporting deadline for the Commission; and

WHEREAS, the work of the Commission can be made more efficient and effective by reducing the number of commissioners.

NOW, THEREFORE, I, John Engler, Governor of the state of Michigan, pursuant to the powers vested in me by the Constitution of the state of Michigan of 1963 and the laws of the state of Michigan, do hereby order that Executive Order 1999-4 be amended to read as follows:

The Michigan Commission on End of Life Care ("Commission") shall consist of 12 members to be appointed by the Governor. The Commission shall serve at the pleasure of the Governor. The Governor shall designate one (1) member of the Commission to serve as its chair and who shall serve as chair at the pleasure of the Governor. Members of the Commission shall attend Commission meetings in person, and shall not delegate their responsibilities to other persons.

No later than February 1, 2001, the Commission shall issue a final report to the Governor and the Legislature containing its recommended model state and institutional policies and the rationale of the Commission supporting their adoption.

The provisions of this Executive Order shall become effective upon filing.

Given under my hand and the Great Seal of the state of Michigan this 24th day of January, in the Year of our Lord, Two Thousand.

(signed) **John Engler**

GOVERNOR

Appendix B: Summary of testimony from public hearings.

In order to hear Michigan citizens' views and concerns directly, the Michigan Commission on End of Life Care held five hearings around the state in the September 2000. The hearing were held in Grayling (September 6th), Detroit (7th), Mt. Pleasant (12th), Grand Rapids (13th), and Marquette (14).

Before the hearings, the Commission distributed a document that outlined its purpose, charge and membership. This was sent to organizations throughout the state that deal with end-of-life care, and the hearings were publicized in various media. The Commission encouraged both oral and written testimony. In particular, the Commission made it known that it was seeking comments on the following key issues:

- Barriers that discourage or prevent access to adequate end-of-life care
- Adequacy of education and continuing education in various professions and disciplines associated with end-of-life care
- Information on limitations of third party reimbursement coverage, public or private, that affect access to adequate end-of-life care
- Information about specific existing resources for citizens planning for end-of-life care for themselves or who are seeking adequate end-of-life care or resources for others.

A total of 140 Michigan citizens attended the five hearings; 99 of them provided testimony. The following summary of their testimony is arranged by subject area — and makes clear how much overlap there is among the areas.

Education.

There is an urgent need for education concerning end-of-life issues at many levels and from many different points of view. End-of-life care should be made part of the curricula of physicians, nurses, and other health care professionals, and continuing education for health care professionals practicing in the field should be mandatory. Education must deal not only with the physical symptoms of patient decline at the end of life but also with the mental, psychological, and spiritual end-of-life needs of terminally ill patients and their families, as well as options for care and the right to refuse care, hospice care, and organ donation. The needs of patients in long-term care facilities were of particular concern. Better education will significantly improve the quality of the care delivered to people at the end of their lives.

Those who survey nursing facilities and other licensed health facilities and agencies to ensure quality and compliance must be educated concerning the unique circumstances of dying patients and the focus of their care. Conflicts arise, for example, between the requirement for nursing facilities to promote rehabilitation and maintenance versus the natural and expected decline of patients who have advanced illness and are approaching the end of their lives.

Finally — and perhaps most important — witnesses cited the need to educate the public, in various settings and beginning early in life, on death and dying, the importance of advance directives, options for care at the end of life including hospice and palliative care, pain management, etc., and related issues.

Pain and symptom management.

There was strong support for the elimination of the state's Official Prescription Program (OPP) on the basis that it has eroded physicians' confidence in pursuing appropriate pain management. Physicians fear incurring sanctions, even when the pain medications they prescribe are medically indicated. (Some of their hesitation may in fact be due to the lack of education in the use of pain medication and resultant lack of current standards of practice in prescribing the medications.) Witnesses said that the original intentions of the OPP should be weighed against the need and right of terminally ill patients to have pain medications prescribed in a timely manner. Michigan is one of only 16 states to have such a law.

The public also needs to be educated about the use of opiate medications that are used to control pain and the acceptability and necessity of this treatment. Both the public and patients in licensed health care facilities may be reluctant to accept prescriptions for pain because of concern about side effects, fear of addiction, lack of proper assessment, lack of knowledge about pharmaceutical management, and uncertainty about insurance consequences.

Witnesses at two of the hearings expressed support for a demonstration project to evaluate current pain management practices, teach key staff the basics of adequate pain management, and institutionalize pain management practices across the health care continuum. The outcome would be recommendations for improving clinical care.

Physicians who are specialists in palliative medicine should be identified on medical staffs and serve as resources for other physicians who are caring for patients at the end of life. In addition, the transition from curative to palliative care needs to be examined both in terms of reimbursement and from a standard-of-care standpoint when the patient is first diagnosed rather than as late as several months prior to the predicted end of life.

Medicare.

Witnesses expressed strong support for elimination of the Medicare rule that hospice care be covered only if the patient's physician's prognosis that death is likely within six months. Because physicians may feel uncomfortable with having to make a prediction about when their patients will die and because prognostication is not an exact science, many physicians do not refer appropriate patients to a hospice until they are in their last weeks or days of life. (Such a prognosis can be particularly difficult in the case of patients with conditions such as Alzheimer's disease, Huntington's disease, or mental illness, and some witnesses suggested that policies be developed that adequately define end of life for people with chronic diseases that cause dementia.) The result is that many patients do not receive the palliative care they need simply because it appears they might live longer than six months.

A related concern was expressed regarding patients in nursing facilities who choose hospice care. For many of them, Medicare covers the cost of the care but the patient and/or family must pay room and board costs; but if a patient chooses skilled nursing care, which does not focus on palliation, all costs are covered.

A Medicare patient can only be re-certified for continued hospice care after the initial six months if the patient's condition declines. In other words, if a patient chooses to receive hospice care in a timely manner and his condition improves, the patient is required to dis-enroll from the hospice after the initial six months, until the patient's condition begins to decline again and he can be readmitted.

Reimbursement.

Reimbursement issues discussed at the hearings ranged far and wide. Among them:

- There exists confusion about how reimbursement works when residents in nursing facilities want to choose to receive hospice care while in the facility. The coordination required has caused facilities to consider whether they will allow the residents to receive hospice care.
- Many third party payors do not offer full coverage for hospice care at all, and many health maintenance organizations do not determine the level of coverage until a nursing assessment is performed by the hospice.
- Pediatric hospice services are usually reimbursed at a per diem rate that is inadequate for patients who require highly specialized supplies and therapeutics and time- and labor-intensive services. Since Medicaid does not generally provide for both hospice and other care, parents can be faced with an agonizing choice. Witnesses suggested that a pediatric reimbursement rate be considered for the specialized care provided to children by a hospice and that dialogue begin between hospice providers and third party payors, including Medicaid, about these issues.
- The standard per diem reimbursement for those who must travel significant distances to deliver hospice care is partly eaten up in travel time and expenses.
- Some believe there is no reimbursement mechanism for physicians who serve as palliative-care consultants to other physicians.

Other issues.

Witnesses at the hearings touched on a number of other topics, including:

- *Organ and tissue donation.* Representatives from the Gift of Life Transplantation Society of Michigan, the National Kidney Foundation, and the Michigan Eye Bank attended each hearing to support the idea of presenting the option of organ and tissue donation to every potential donor family.
- *Long-term care settings.* The state regulations for long-term care facilities generally conflict with the philosophy of hospice care and palliative care. The focus for long-term care facilities is on rehabilitation and maintenance for their residents. But for a person enrolled in hospice, a decline is expected, yet state surveyors see that decline in a patient's condition in a long-term care facility as a negative for the facility, increasing the chance that the facility will receive a citation. Witnesses suggested that a joint task force of nursing home, hospice and Department of Consumer and Industry Services representatives be appointed to develop policies and procedures in long-term care facilities to improve communication between the facilities and hospice in order to improve access to end-of-life care.
- *Advance directives.* Many felt that a statewide awareness campaign should be launched to educate people about advance directives and to give them an opportunity to talk with their loved ones about their desires and wishes for health care, particularly if they become incapacitated. Most felt the discussion about advance directives should start with the individual's physician. Some felt that all patient records should have evidence of advance

directives; and the suggestion was made that this information be added to the back of driver licenses. Finally, there was support for establishing some mechanism to ensure that health care providers follow advance directives when they do exist.

- *Probate Court guardianship.* Concerns were raised about those ill and vulnerable patients who, having no one to speak for them, are then assigned a Probate Court guardian. One investigation found that most guardians will not support end-of-life decision-making for a variety of reasons. Witnesses recommended establishment of an accountability system for end-of-life decision-making and end-of-life standards for Probate Court guardians.
- *Diverse populations.* Witnesses testified about the need to address and understand the unique issues of diverse populations as they relate to the end of life. Based on cultural beliefs, one's approach and perspective on end-of-life care varies tremendously.

Appendix C: Barriers to end-of-life care.

Barriers to providing appropriate care for individuals at the end of life stem primarily from limited resources, shortcomings in the health care system and society's difficulties in dealing with sensitive end-of-life issues. The Commission recognized immediately that it would be necessary to set priorities among the many barriers it found and focus efforts in areas in which an immediate impact would be possible. The following are high-priority areas for identification and amelioration of barriers: consumer empowerment, professional education, pain and symptom management, and insurance and regulations.

Summary of barriers.

Consumer empowerment. The biggest single barrier is lack of education in end-of-life issues such as patient rights, advance directives, designation of surrogates for end-of-life decision-making, and the options for treatment, including hospice and palliative care. Patients often lack access to palliative care specialists and do not understand the relationship between curative and palliative care; nor do they understand that pain and symptoms can be managed without forgoing all options for curative care. Physicians often fail to present all options to patients, and both physicians and surrogates often lack a good understanding of patients' goals and preferences for health care.

Professional education. Perceived barriers included lack of professional education and continuing education of health care professionals in basic areas of diagnosing and treating patients who have life-threatening conditions; inability to identify when a condition or illness is nearing the terminal stage; failure to offer patients choices within a range of curative and palliative modalities; and lack of competence and experience in conducting compassionate dialogue with patients and families on end-of-life issues. Of equal if not greater concern was the lack of understanding of basic patient rights to informed consent, including the right to accept or reject specific modalities of care.

Pain and symptom management. These barriers include lack of knowledge on the part of both patients and clinicians that patients have a right to have their pain assessed, treated, and relieved; lack of understanding by patients of how best to communicate pain and even whether it is acceptable to do so; lack of knowledge by professionals of how to elicit and measure patients' reports of pain and relief of pain; lack of knowledge of the full range of pharmacological and nonpharmacological modalities for treating pain; inadequate understanding of the side effects of pain medication; and misconceptions concerning potential addiction. Among health care providers, there is insufficient education in palliative care and all its components; insufficient knowledge about symptoms of the end of life other than pain (e.g., dyspnea, nausea, anorexia, edema, fatigue, constipation, diarrhea, or cognitive disturbances); frequent failure to conform to current standards and clinical practice guidelines for pain assessment and relief; fear of regulatory scrutiny for prescribing controlled substances; and fear of other restrictive state regulation.

Insurance and regulations. Among many reimbursement issues are the lack of and gaps in insurance coverage for some end-of-life services based on current models of care and today's finances; the inadequacy of hospice reimbursement for the costs of palliative care, especially

when the patient does not forgo all curative modalities; and eligibility restrictions for appropriate but expensive therapies.

A cause of significant concern is the Medicare requirement that coverage of hospice care begin after a prognosis of six months or less of life remaining (a regulation based on cancer and not including other terminal illnesses). This can put a patient in the position of having to choose between palliative and curative care. The reluctance of health care providers to recommend patients choose hospice care earlier in the disease course results in late referrals and use of more crisis services, which are more costly and deprive the patient of the pain and symptom management at which hospice programs particularly excel.

Regulatory issues include the limitations of end-of-life care for terminally ill patients in state mental hospitals, the limitations on end-of-life care treatment options placed on providers by managed care relationships, inadequate dissemination of available knowledge by payors regarding end-of-life issues, and the absence of simple and universal processes designed to encourage the beneficiary to keep advance directives current. Quality assurance issues include lack of consistent reporting of data on end-of-life care, lack of benchmarks for measuring and evaluating patient quality of care outcomes near the end of life, and lack of consistency in standards of care across the continuum.

The Commission encountered and considered many barriers to effective and compassionate end-of-life care in these and other areas. What follows is a more detailed list of these barriers.

Barriers in the health care professions.

Attitudinal barriers:

- Resistance to “giving up,” i.e., trying to cure the patient despite a terminal prognosis
- Equating the patient’s death with failure on the part of the health care professional
- Lack of respect for patient autonomy
- Difficulty making the mental and emotional shift to accept and embrace end-of-life care
- Anxiety about death; difficulty in dealing with their own and their loved ones’ deaths
- Discrepancies between health care professionals’ beliefs about patients’ prognoses and patients’ beliefs
- Feelings of distress and frustration resulting from day-to-day involvement in managing unrelieved psychosocial pain.

Knowledge barriers :

- Insufficient coverage in medical and nursing education of end-of-life issues
- Lack of knowledge base for proper diagnosis and prognosis
- Lack of education and understanding of the relationship between curative and palliative care
- Lack of education in how to communicate with terminally ill patients and their families, and lack of competence and experience in conducting compassionate dialogue with patients and families on end-of-life issues
- Lack of education in pain and symptom management
- Inadequate understanding of the real versus perceived side effects of pain medication
- Misconceptions and myths about potential addiction to pain medication

- Insufficient knowledge about symptoms of the end of life other than pain, e.g., dyspnea, nausea, anorexia, edema, fatigue, constipation, diarrhea, and cognitive disturbances
- Lack of knowledge about goal-setting for treatment choices
- Lack of knowledge of basic patient rights to informed consent and the right to accept and reject treatment.
- Lack of appreciation for the use of ethics committees or second opinions in resolving ethical dilemmas and conflicting views on medical and ethical questions.

Competence barriers

- Lack of competence in available standards for pain and symptom assessment and relief
- Lack of communication skills on end-of-life issues.

Barriers among patients and families.

Attitudinal barriers:

- Determination to seek curative treatment despite terminal prognosis
- Inability to accept terminal prognosis
- Difficulty making the choice to seek palliative treatment as a main goal rather than curative treatment
- Fear or unwillingness to engage physicians in dialogue on end-of-life issues
- Concern about distracting the physician from treatment of underlying disease by focusing on need for comfort
- Reluctance to report pain
- Fear that pain means the disease is worse
- Fear of addiction to pain medication
- Concern about not being a “good” patient
- Belief in some cultures that suffering is deserved
- Frustration with health care providers because of perception that they don’t always take symptoms seriously
- Fear of loss of access to primary caregivers who have knowledge of the patient’s wishes and value system as the patient receives care in a variety of settings
- Lack of assurance that all health care providers have knowledge consistent with the patient’s values and wishes
- Feeling that personal and family caregivers’ expertise in caring for their loved one is ignored
- Patient and family perception that medical routines and the choice for hospice are not individualized
- Conflicts within families regarding goals of treatment and needs of patient.

Knowledge barriers:

- Lack of information about hospice care or palliative care
- Lack of knowledge about how to find palliative care specialists
- Lack of education about how to best report and communicate pain
- Lack of understanding about how pain medication works and a resultant reluctance to take pain medication
- Inadequate understanding about the side effects of pain medication
- Misconceptions about potential addiction to pain medication

- Lack of understanding about basic patient rights
- Lack of understanding about advance directives and end-of-life decision-making
- Failure to take responsibility to see that advance directives are accessible and understandable to providers and family members
- Lack of information about living with terminal illness, treatment choices, and changes likely to occur as disease progresses
- Failure of surrogates to accurately report patients' preferences

Cultural and societal barriers.

- Discomfort with and denial of death
- Inadequate education in differing religious and cultural issues relating to death and dying. that can affect end-of-life care
- Disparity of views among cultures on end-of-life issues and on the essence and process of decision-making
- Distrust of the health care system in general
- Failure to recognize the differences between religion and spirituality
- Lack of social support, family support, and pastoral care
- Society's tendency to isolate the dying.

Systemic barriers.

Barriers to delivery of care:

- Fragmentation of health care system across the continuum, which interferes with comprehensive care and occasionally produces counterproductive responses in the health care system
- Lack of consistency among health care providers in keeping track of advance directives.
- Failure to identify who among health care providers is responsible for providing information and resources to patients and families
- Problems with availability of or access to end-of-life services
- Overtreatment of patients at the end-of-life in inappropriate settings
- Lack of comprehensive palliative care services across the continuum of health care settings
- Limitations of the traditional medical model for patients with palliative care needs
- Lack of palliative care teams in hospitals.

Barriers related to reimbursement:

- Lack of any health care insurance coverage
- Lack of comprehensive coverage for end-of-life services based on current models of care and today's finances
- Inadequacy of hospice reimbursement model for covering elements of curative care
- Eligibility restrictions for appropriate but expensive therapies
- Lack of insurance and gaps in insurance coverage and other reimbursement for some end-of-life services
- Fear by health care providers that if a patient chooses hospice care too early in the disease course, late referrals to hospice and use of more crisis services, which cost more, could result

- Lack of adequate reimbursement to providers for communication regarding advanced planning.

Barriers related to regulatory issues:

- Medicare's requirement that coverage of hospice care must begin after a prognosis of six months or less of life (a determination based on cancer and not including other terminal illnesses)
- Lack of requirements that professionals obtain continuing education in end-of-life care
- Concern about regulation of controlled substances
- Fear on part of managed care organizations (MCOs) that focusing on palliative care makes it seem as though the MCO is trying to end the lives of patients whose care is costly
- Interference of some productivity quotas with ability to assess and respond to actual needs of patients and their families
- Restrictive state regulation and monitoring of pain medications
- Medicare requirement that patient choose between palliative and curative care
- Limitations of end-of-life care for terminally ill patients in state mental hospitals
- Absence of National Committee for Quality Assurance or Health Evaluation Data Information System focus for MCOs
- Limitations on end-of-life care treatment options placed on providers by managed care relationships
- Threat of fraud and abuse by health care provider as a perceived concern of Medicare and Medicaid
- Fear on part of health care providers of the Office of the Inspector General for overpayment liability for patients who live longer than six months while receiving hospice care (outliers)
- Low priority given to pain and symptom treatment
- Inadequate dissemination of available knowledge by payors on end-of-life issues
- Inadequate payor communication with terminally ill patients
- Outdated materials on end-of-life care distributed by payors
- Inadequate community/physician education programs by payors
- The absence of simple and universal processes to encourage the insured to keep advance directives current.

Barriers within the quality assurance realm:

- Lack of consistent reporting of data on end-of-life care
- Lack of benchmarks for measuring and evaluating quality of care outcomes near the end of life
- Lack of consistency in standards of care across all settings where health care is delivered.

Barriers of diversity:

- Variation in care by patient age, race, or geographic location.
- Lack of cultures represented by and reflected among health care professionals.
- Lack of access to health care for poor, and to end-of-life care in particular.

Barriers in hospice programs.

These include:

- Misperceptions of “hospice” as a place rather than as a model of care
- Late patient referrals to hospice programs
- Belief that “hospice” connotes “death” and “giving up.
- Impression on part of hospice providers that they are excluded from regulatory scrutiny
- Poor communication with health plan administrators, physicians, or case managers
- Lack of consistent standards among hospice programs as to whom they accept and when
- Inappropriate discussion with family members and patients about payment or coverage or other administrative matters concerning the hospice organization and the health maintenance organization
- The view that some hospice organizations are more inclined to accept cancer patients than those with other conditions
- Lack of consistent data collection and reporting
- Lack of standards of care
- Belief that choosing hospice takes away hope for the patient
- Belief that choosing hospice represents failure by the health care provider
- Lack of education for health care professionals concerning hospice admissions criteria and services available
- Health care professionals’ fear of losing control of a patient once the patient has chosen hospice care.

Barriers in long-term care facilities.

Attitudinal barriers:

- Federal regulatory guidelines resulting from the Omnibus Budget Reconciliation Act of 1987, also known as the National Nursing Home Reform Act, and the Centers for Medicare and Medicaid Services (CMS) Prospective Payment Program that encourage restorative or rehabilitative care rather than basic comfort+ care
- Impact of regulations on health care professionals’ ability to strike a balance between working to ensure a good death and complying with regulatory guidelines
- Disagreement among surveyors from CMS and state agencies and health care providers about whether all appropriate interventions were implemented and whether their implementation was sufficiently aggressive
- Tendency in this environment to view death with suspicion or as a failure of care
- Lack of commitment on part of some long-term care facility leadership to the process of implementing strategies to improve end-of-life care
- Conflicts between hospice and long-term care facilities regarding who is in charge of each patient’s care.

Knowledge barriers:

- Lack of quality indicators to help provide residents with a “good” death
- Lack of inclusion of end-of-life care quality indicators among the 29 indicators used by CMS and state surveyors to identify areas in which facilities may be providing inadequate care
- Inadequate recruitment and training of skilled certified nursing assistants

- Inadequate education of health care providers in end-of-life care
- Inadequate education about pain medications and their use
- The perception that there are limited options for use of pain medications for older adults due to unique side effects and ineffectiveness in this population
- Inadequate preparation of long-term care facilities for implementation of clinical practice guidelines
- Outdated information systems.

Competence barriers:

- Failure on part of the care team to make the goals of treatment explicit
- Failure on part of the care team to document reasons for not pursuing all options of care
- Inadequacies in care resulting from the environment in long-term care facilities, including the over- or underutilization of treatment, untimely commencement of hospice care, poor clinical care in the palliation of symptoms, and poor communication about prognoses and treatment preferences
- Lack of a re-evaluation mechanism for use of pain medications for non-malignant pain
- Poor check-and-balance system between a long-term care facility's health care provider and its consulting pharmacist
- Underuse of non-pharmacologic techniques for pain relief
- Poor communication with the family.
- High staff turnover rate.
- Lack of clinical practice guidelines for end-of-life care.
- Unevenness of knowledge and skills between long-term care facility care providers and hospice care providers
- Inadequate coordination between long-term-care facilities and hospice care providers
- Lack of communication systems between nursing facilities and primary care providers.

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Appendix D: Survey instruments

- 1. Survey of Michigan physicians concerning the Michigan Official Prescription Program.**
- 2. Survey of medical residents/fellows.**
- 3. Survey on Hospice, Palliative, and Other End-of-Life Care**

Michigan Commission on End of Life Care
c/o Palliative Care Education and Research Program
Michigan State University
B110 Clinical Center
East Lansing, MI 48824

October 25, 2000

Dear Michigan Physician,

On behalf of the Michigan Commission on End of Life Care, we are requesting your assistance to better understand how Michigan physicians provide pain and symptom management for patients.

The twelve-member Commission was created by Governor Engler to assess and make recommendations to improve access to end of life care, including pain management. Commission members include three physicians, and its findings and recommendations will be presented in a final report to the Governor and the Legislature by February 1, 2001.

The Commission has appointed a Task Force on the Official Prescription Program (OPP). The Task Force includes Commission members along with members of the Policy Subcommittee of the Michigan Advisory Committee on Pain and Symptom Management, which is also reviewing the OPP. The Task Force is charged to evaluate the OPP, and assess its impact on access to effective pain management.

Enclosed is an anonymous questionnaire to help us gain information about physicians' participation in and experiences with the OPP. We ask you to complete the questionnaire and return it to us by **November 30, 2000** or as soon as possible. We estimate that it will take **less than five minutes** to complete the questionnaire; then fold and seal before mailing. Your participation is voluntary, and you indicate your agreement by completing and returning the questionnaire. Your responses are anonymous, and your privacy will be protected to the maximum extent allowable by law. In fact, there is nothing on the questionnaire to identify you as an individual. Contact Rishan Butler, Staff Director for the Michigan Commission on End of Life Care if you have any questions about this survey at (*phone number*). If you have questions about your rights as a human subject, contact Dr. David Wright, Chair, University Committee on Research Involving Human Subjects, at (*phone number*).

Your cooperation in completing and returning this questionnaire is critical to achieving our goal that there be sufficient data on which to base our assessment and any recommendations. Together, we can improve the quality of end of pain management practices in Michigan and the quality of life for Michigan citizens. Thank you for your support of this important endeavor.

Sincerely,
Karen S. Ogle, MD, Chair
Michigan Commission on End of Life Care

Billy Ben Bauman, MD
President, Michigan State Medical Society

Gerald E. Brenton, DO
President, Michigan Osteopathic Society

MICHIGAN COMMISSION ON END OF LIFE CARE
SURVEY ON MICHIGAN OFFICIAL PRESCRIPTION PROGRAM

The Michigan Official Prescription Program (OPP) requires the use of special prescription forms to prescribe Schedule II narcotics (for example: Percocet, Morphine) in the outpatient setting. The OPP was formerly the Michigan Triplicate Prescription Program.

1. What is your primary area of medical specialty? (Family practice, internal medicine, emergency medicine, surgery, psychiatry, etc.) Please specify the area:

What are your other areas of medical specialty? Please specify the areas:

What year did you graduate from medical school? _____

How many years have you practiced in Michigan? _____

2. Male Female

3. In what clinical settings do you practice? Please check all that apply.

- | | |
|--|--|
| <input type="checkbox"/> Office or clinical | <input type="checkbox"/> Long term care |
| <input type="checkbox"/> Acute care hospital | <input type="checkbox"/> Hospice/palliative care |
| <input type="checkbox"/> ICU/CCU | <input type="checkbox"/> Home care |
| <input type="checkbox"/> Emergency room | <input type="checkbox"/> Other – Please specify: |

4. In what geographic settings do you practice?

- Urban
 Suburban
 Rural (Lower Peninsula)
 Rural (Upper Peninsula)

5. Do you use Michigan Official Prescription Program (OPP) prescriptions?

- Yes No

If NO – Please check ALL of the reasons that apply to your situation (then go to Q12)**:

- a. I am not familiar with the OPP
 b. I do not know how to obtain OPP prescription pads
 c. I do not like to use a second prescription form
 d. OPP prescription forms increase my cost to practice
 e. I do not want to care for patients who need Schedule II narcotics
 f. I do not feel qualified to prescribe Schedule II narcotics
 g. I am concerned that my patients may become addicted to Schedule II narcotics
 h. I am concerned about “doctor shoppers” or people who seek narcotics for inappropriate use
 i. I am concerned that opioids may depress respiration and hasten a patient’s death
 j. Schedule II opioids are not needed in my practice. If so, please explain: _____
 k. Other (please specify) _____

If YES – For which types of patients do you prescribe Schedule II narcotics? Please select all that apply to your practice:

- a. Terminally ill patients
- b. Patients with chronic pain associated with a malignancy
- c. Patients with chronic pain NOT associated with a malignancy
- d. Patients with acute pain (Post-surgical / Post-injury / Acute medical problem)
- e. Other (please describe): _____

6. Have you had any problems with the OPP prescriptions that you write?

- No
- Yes – Please check all that apply to your situation:
 - a. Pharmacists are reluctant to fill emergency telephone orders
 - b. Pharmacists are uncertain about whether OPP prescriptions can be filled for more than a thirty (30) day supply
 - c. Insurance companies have unrealistic limits on what constitutes a thirty (30) day supply
 - d. Pharmacists do not want to fill my prescriptions for Schedule II narcotics
 - e. Some of my patients do not have access to pharmacies that stock adequate supplies of Schedule II narcotics
 - f. Pharmacists question my prescriptions

7. Has the use of OPP forms had any effect on your practice?

- No
- Yes (please elaborate: _____

8. I am concerned about regulatory scrutiny of my practice if I prescribe Schedule II narcotics.

- Yes
- No

9. I worry about sanctions for high or inappropriate use if I prescribe Schedule II narcotics.

- Yes
- No

10. Do you have any concerns about the OPP that are not covered above?

- No
- Yes (please) describe) _____

Thank you very much for your participation. We welcome any additional comments or suggestions that you would like to share regarding the OPP:

— Postage is paid for your prompt reply. Please fold along dotted line, seal with tape, and mail today. —

**** Editor's note:** In Q #5, with a NO response, the reader should have been directed to "then go to Q10", but the error was not discovered until after all surveys had been returned and analyzed.

MICHIGAN COMMISSION ON END OF LIFE CARE
Survey concerning end-of-life care training in Michigan residency/fellowship programs

Section 1: Program information (PLEASE COMPLETE FULLY):

Specialty of your residency/fellowship program:

Total number of residents/fellows enrolled:

Section 2: End-of-Life care training

1. Does your program offer formal training in end-of-life care?
 Yes (go to Question 2) No (go to Question 5)

2. Is this training required or elective? (*Choose only one*)
 Required (go to Question 3)
 Elective (go to Question 4)
 Both (answer Question 3 and Question 4)

3. What is the format of the required training: (*Choose all that apply*)
 a. Lecture (hours)
 b. Small group discussions (hours)
 c. Required readings
 d. Clinical rotations/experiences (hours/days/weeks)
 e. Other (Please describe, including time commitment (hours/days/weeks):

4. What is the format of the elective training: (*Choose all that apply*)
 a. Lecture (hours)
 b. Small group discussions (hours)
 c. Required readings
 d. Clinical rotations/experiences (hours/days/weeks)
 e. Other (Please describe, including time commitment (hours/days/weeks)

5. Do you believe that end-of-life care is covered informally elsewhere in your curriculum, aside from specific required or elective training?
 Yes. Please describe:

 No

6. Overall, how would you evaluate the formal and/or informal training that your residents/fellows receive in end-of-life care?
 Excellent Adequate Inadequate

Section 3: Pain Management

7. Does your program offer formal training in pain management?

Yes (go to Question 8) No (go to Question 11)

8. Is this training required or elective? (*Choose only one*)

Required (go to Question 9)
 Elective (go to Question 10)
 Both (answer Question 9 and Question 10)

9. What is the format of the required training: (*Choose all that apply*)

- a. Lecture (_____ hours)
 b. Small group discussions (_____ hours)
 c. Required readings
 d. Clinical rotations/experiences (_____ hours/days/weeks)
 e. Other (Please describe, including time commitment (hours/weeks/days):

10. What is the format of the elective training: (*Choose all that apply*)

- a. Lecture (_____ hours)
 b. Small group discussions (_____ hours)
 c. Required readings
 d. Clinical rotations/experiences (_____ hours/days/weeks)
 e. Other (Please describe, including time commitment (hours/weeks/days):

11. Do you believe that pain management is covered informally elsewhere in your curriculum, aside from specific required or elective training?

Yes. Please describe: _____

 No

12. Overall, how would you evaluate the formal and/or informal training that your residents/fellows receive in pain management?

Excellent Adequate Inadequate

Section 4: Hospice

13. Does your program offer formal training in a hospice program?

Yes (go to Question 14) No (go to Question 18)

14. Is this training required or elective? (*Choose only one*)

Required (go to Question 15)
 Elective (go to Question 16)
 Both (answer Question 15 and Question 16)

15. What is the format of the required training: *(Choose all that apply)*

- a. Lecture (hours)
- b. Small group discussions (hours)
- c. Required readings
- d. Clinical rotations/experiences (hours/days/weeks)
- e. Other (Please describe, including time commitment (hours/days/weeks):

16. What is the format of the elective training: *(Choose all that apply)*

- a. Lecture (hours)
- b. Small group discussions (hours)
- c. Required readings
- d. Clinical rotations/experiences (hours/days/weeks)
- e. Other (Please describe, including time commitment (hours/days/weeks):

17. Are residents/fellows involved in care of individual patients entered in a hospice program?

Yes No

18. Do you believe that hospice care is covered informally elsewhere in your curriculum, aside from specific required or elective training?

Yes. Please describe: _____

_____ No

19. Overall, how would you evaluate the formal and/or informal training that your residents/fellows receive in hospice care?

Excellent Adequate Inadequate

20. Are any faculty members in your residency/fellowship program formally involved in a hospice program?

Yes No (Go to Section 5)

22. What is the role of the faculty member(s) in the hospice program: *(Check all that apply)*

Medical director

Other (please specify): _____

Section 5: Curriculum content

For each of the following content areas, please evaluate your program. Check all of the boxes that describe the coverage of each topic in your curriculum.

Topic	Required of all residents	Electives offered	Not included in program
Pain management			
Control of symptoms other than pain			
Determining prognosis			
Spiritual needs assessment			
Insurance regulations related to hospice care			
Bereavement care			
Care of the family of the dying patient			
Home care for dying patients			

We would appreciate any additional comments regarding the training you offer in the areas of pain management, end-of-life care and hospice care.

Thank you VERY MUCH for completing this survey.

Please return the survey BY AUGUST 24 to:

FAX number

OR

Michigan Commission on End of Life Care
 Department of Community Health
 Attn: *Project Coordinator's name here*
 6th Floor Cass Bldg.
 320 Walnut Street
 Lansing, MI 48913

Michigan Division of Insurance and Michigan End-of-Life Commission

Survey on Hospice, Palliative, and Other End-of-Life Care

The Michigan Commission on End-of-Life Care has been charged by the Governor with the task of reporting important issues and barriers with regard to end-of-life care in Michigan. Included in the report will be information on the degree to which hospice, palliative care and other end-of-life care is covered by private and public health plans. We appreciate your cooperation in completing this survey of private health plans and third party reimbursement programs.

If you have more than one coverage type (product line) AND different coverage types or if you cover hospice, palliative or end-of-life care differently,

PLEASE MAKE COPIES OF THIS SURVEY AND FILL THE SURVEY OUT SEPARATELY FOR EACH DIFFERENT TYPE OF END-OF-LIFE COVERAGE.

Company name _____

Person completing survey _____

Phone number to call with questions concerning survey responses _____

1. Type of health coverage provided in MICHIGAN: (Check all that apply to the information given in this copy of the survey.)

- indemnity health plan
- HMO (commercial only)
- PPO
- TPA
- Medicare supplemental
- Other Please explain _____

2. How many MICHIGAN employer group contracts do you have with this coverage?

3. How many MICHIGAN member/covered lives _____ do these contracts and any individual contracts cover? (Please estimate the number of certificates and/or covered lives, if necessary.)

HOSPICE COVERAGE IN MICHIGAN

4. Do any of your health insurance contracts or riders include hospice care? Yes No
If "Yes", please complete the following questions; if "No," skip to question 6.
- a. Please attach and return with the survey a description of this benefit as it appears in group policy.
 - b. How many contracts include hospice coverage? _____ contracts
 - c. How many member lives or covered lives are included _____ (please estimate if not known)
 - d. What is the employer's average cost per month to include hospice coverage in their health plan?
individual \$ _____
individual and spouse \$ _____
family \$ _____
 - e. How many hospice patients did you have in most recently reported year?
_____ patients _____ year
 - f. What is the maximum dollar amount of hospice coverage allowed?
\$ _____ or no limit
 - g. What is the maximum number of days of hospice coverage?
_____ days or no limit
 - h. Can the maximum number of days or dollars be increased? Yes No
 - i. Is pre-certification/prior authorization required for hospice coverage?
Yes No
 - j. Are curative benefits reduced for the terminal illness if hospice is elected?
Yes No
 - k. Is there a deductible that must be met for hospice care? Amount? _____ No
 - l. Is there a co-pay requirement (in network)? Amount? _____ No
 - m. Is there a co-pay requirement (out of network)? Amount? _____ No
 - n. How is reimbursement for hospice services structured? Per case (capitated)
Per diem (comprehensive) Per service (unbundled)
 - o. Do capitated or comprehensive rates vary by intensity of care delivered?
Yes No
 - p. Does hospice care cover the following sites:
hospice in hospital _____ Yes No
in-patient hospice facility (stand alone) _____ Yes No
hospice in nursing or extended care facility _____ Yes No
in-home hospice _____ Yes No
 - q. Does hospice care cover the following services:
professional home nursing _____ Yes No covered elsewhere
homemaker _____ Yes No covered elsewhere
home health aide _____ Yes No covered elsewhere
individual counseling _____ Yes No covered elsewhere
family/ bereavement counseling _____ Yes No covered elsewhere
durable medical equipment _____ Yes No covered elsewhere

- drugs _____ Yes No covered elsewhere
- physical and other therapies _____ Yes No covered elsewhere
- medication management _____ Yes No covered elsewhere
- case management _____ Yes No covered elsewhere
- respite care _____ Yes No covered elsewhere

5. Do you provide any of the following:
- a. Patient educational materials on hospice Yes No
 - b. Physician educational materials on hospice Yes No
 - c. Case finding /case management to identify individuals who may benefit from hospice? Yes No
6. Do you offer Medicare supplemental insurance? Yes No
 If "Yes," please complete the following question; if "No," skip to question 8.
7. Do you offer hospice benefits as part of this supplemental insurance? Yes No
 If "Yes," please explain:

NON-HOSPICE PALLIATIVE CARE IN MICHIGAN

8. Do you reimburse hospital admissions for palliative care **outside of the hospice benefit?**
 (DRG code V667) Yes No
9. Do your hospital inpatient benefits include the following care for dying patients (unrelated to surgery or rehabilitation)?
- pain and symptom management _____ Yes No
 - acute dying _____ Yes No
 - respite care _____ Yes No
10. Do you reimburse for physician, psychologist or nurse practitioner consultations for palliative care? (CPT Code 99201-99499) Yes No

11. Is there any other information you would like to tell us about palliative care coverage?

OTHER END-OF-LIFE CARE IN MICHIGAN

12. Do you provide outpatient pharmacy coverage? Yes No
13. Do you cover any of the following for pain and symptom management **outside of the hospice benefit**?
- | | | |
|---|------------------------------|-----------------------------|
| opioid medications _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| chemo-therapy _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| radio-therapy _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| nerve block techniques _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| implantable pumps _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| durable medical goods such as pumps and
tubing for IV infusion systems _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| central venous catheterization as access for
infusion therapy _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| pain management clinic costs _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| psycho/social counseling for patient _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| bereavement counseling for family _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| acupuncture _____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
14. Do you limit payments for these pain and symptom management techniques? Yes No
If "Yes," please explain:
-
-
-
15. Do you employ or pay for a care manager to coordinate care at end-of-life (e.g., help make transition between hospital, nursing home and hospice care)? Yes No
16. If you are a managed care organization (MCO), do you have a service agreement with:
- | | | | |
|------------------------------|------------------------------|-----------------------------|-------------------------------------|
| a pain center | Yes <input type="checkbox"/> | No <input type="checkbox"/> | not an MCO <input type="checkbox"/> |
| a hospice provider | Yes <input type="checkbox"/> | No <input type="checkbox"/> | not an MCO <input type="checkbox"/> |
| a palliative care specialist | Yes <input type="checkbox"/> | No <input type="checkbox"/> | not an MCO <input type="checkbox"/> |
17. Is there any other information you would like to tell us about end-of-life benefit coverage?
-
-
-

Please mail this completed survey to:

name, Div. of Insurance, P.O. Box 30220, Lansing, Michigan 48909-7720

Or fax it to her at: *number*

VIII(E). Findings of survey on private health insurance coverage.

This report responds to the following charge in Executive Order 1999-4, by which Governor John Engler established the Michigan Commission on End of Life Care: “The Commission shall survey availability and cost of public and private insurance coverage for hospice, pain management, and palliative care.”

The survey of insurers and managed care organizations was a joint effort of the Commission, the Michigan Department of Community Health (MDCH), and the Division of Insurance within the Michigan Department of Consumer and Industry Services. The Division of Insurance provided information on licensure requirements for insurers, assisted in piloting the survey questionnaire, identified organizations to be surveyed, distributed and collected the surveys, and assisted in the review and editing of this report. The MDCH staffed the Commission, provided technical assistance, and funded this study.

Background.

Variations in public and private health insurance reimbursement for end-of-life care services are a concern to many health care providers, who observe that at least some types of end-of-life care services are either not covered or are reimbursed at less than the cost of care.¹ A Robert Wood Johnson Foundation-funded project on end-of-life care has found that many physicians mistakenly believe that the current coding system used to bill insurers for physician services does not include codes related to hospice and palliative care, when in fact these services are covered.² In fact, most beneficiaries also lack an understanding of what their health plans cover and do not cover for end-of-life care. For instance, only 36.5 percent of adult respondents said their insurance covered hospice care, while 52.5 percent did not know if their insurance even covered hospice care, according to the 1999 Michigan Behavior Risk Factor Survey conducted by MDCH.³

End-of-life care may include services such as hospice care, pain management, and palliative care. All these services are intended to provide the patient with comfort and care during advanced or terminal illness. Of concern to the Commission is the availability and adequacy of insurance coverage for these services.

Commission findings.

The Commission’s general findings are based on the efforts of the Insurance Project Work Group, which it established to investigate and analyze specific issues concerning public and private health insurance coverage related to end-of-life care. Because information on private insurance coverage for end-of-life care was not readily available, the work group developed and conducted a statewide survey of insurers and health care coverage providers, including commercial insurers, not-for-profit health care corporations, and managed care organizations. The work group also reviewed relevant publications and met with local and state experts on insurance and end-of-life care. The findings by the Commission are a compilation of the survey results and excerpts from other state and national research.

The following are highlights of the Commission's findings:

- Most insurers and managed care organizations provide for end-of-life care services through various plans.
- These plans vary in limitations and restrictions by type of insurer or coverage provider, but they provide for most services in most settings.
- Most beneficiaries covered by private health insurance had a lower utilization rate for end-of-life care services than the general population.

These results must be considered in light of all the other resource information that contributes to the understanding of this topic. (For limitations of the survey, see Survey overview and analysis section.) The findings summarized below are a compilation of survey data and other research on end-of-life care.

Summary of findings.

General. Hundreds of health insurance policy writers are licensed in Michigan, but the top 20 or so write most of the health insurance coverage, according to the Division of Insurance. The work group focused on this group of insurers and managed care organizations to capture a snapshot of private health insurance coverage in Michigan. Ten of the top insurers and managed care organizations that provide coverage through 12 plans to more than 6.1 million beneficiaries responded to the Commission's survey. For this survey, these plans were divided into three coverage groups: indemnity (commercial and nonprofit insurers writing expense-incurred policies and indemnity benefit policies), third-party administrators (TPAs), and managed care organizations (i.e., health maintenance organizations, or HMOs).

In 1999, more than half of all Americans who had health insurance were enrolled in some kind of managed care plan,⁴ but managed care has not penetrated the market in Michigan to that extent. The Commission's survey found that most of the covered lives identified were covered by either an indemnity or TPA plan, while managed care plans covered slightly less than a third.

Hospice programs. Hospice care is the service most frequently associated with end-of-life care. In 1999, approximately 25,400 patients were served by hospice programs in Michigan, or almost 26 hospice patients per 10,000 population.⁵

Nationally, about three-fourths of the people who use end-of-life care each year are 65 or older and are probably covered by Medicare.⁶ In 1999, Medicare paid for 80 percent of hospice patient care, Medicaid for 6 percent, and other payors (commercial and private insurers) for 14 percent in Michigan.⁷ Beyond hospice services, little is known nationally about the financing of end-of-life care services.⁸

The number of Medicare beneficiaries choosing hospice services nationally has increased substantially. In 1998, nearly 360,000 Medicare beneficiaries enrolled in a hospice program, more than twice as many as in 1992.⁹ Of Medicare beneficiaries who died in 1998, about one in five used the hospice benefit.¹⁰

Even with the growth in hospice use, only 19 percent of Medicare beneficiaries who died in 1998 received hospice services. According to the National Hospice and Palliative Care Organization,

when the number of deaths nationwide is adjusted to reflect only those whose diagnoses (e.g., Alzheimer's disease and cancer) are likely to make them candidates for hospice care, the proportion of dying patients cared for in a hospice program is probably about 40 percent.¹¹

Although more Medicare beneficiaries are receiving hospice services, on average, they are receiving fewer days of care than beneficiaries of the past. From 1992 to 1998, the average length of stay declined 20 percent (from 74 to 59 days), and the median length of stay declined 27 percent (from 26 to 19 days).¹²

According to the Commission's survey, almost all beneficiaries under plans responding were covered for hospice care. However, only a small proportion of beneficiaries, or 4.2 people per 10,000 population, received hospice services in 1999. This was significantly lower than the overall state rate of 26 people per 10,000 population. One reason for this difference might be the fact that most private coverage is employer-based, with beneficiaries likely to be under age 65 and thus less likely to need hospice care. Coverage of hospice services in all settings (i.e., hospital, home, long-term care facility) closely resembled that provided by Medicare and Medicaid, except for some limitation for homemaker services.

The survey findings also showed that a majority of beneficiaries had dollar and days-of-care maximums for hospice services in their coverage plan. Managed care organizations (MCOs) were less likely than indemnity plans and TPAs to place caps on dollars or days of care. MCOs did require pre-certification or authorization but did not reduce curative care reimbursements. Very few beneficiaries had a deductible or co-pay for hospice care. Frequently, but not always, reimbursement by MCOs for hospice care was on a per diem basis, and usually rates did not vary by intensity of care. Indemnity plans generally reimbursed on a per diem basis, and rates varied by intensity of care, much like Medicare.

Pain management. Pain management is an essential part of hospice and palliative care. Typically, pain management begins with an assessment of the type, severity, and impact of pain and other symptoms, followed by development of a plan, treatment and follow-up. Mild pain can be treated with a variety of drugs and other therapies. For moderate to severe pain, opioid analgesics including morphine and other opioids are indispensable. Treatment of pain should vary according to the symptoms and needs of the patient.¹³

The Commission's survey found that most beneficiaries were covered for "other end-of-life care services outside of hospice," including types of pain management (e.g., opioid medications, pain management clinic costs). When asked specifically about more defined types of pain management, fewer than a third of the beneficiaries were covered for "palliative pain and symptom management" through their coverage plans. Moreover, those covered by an indemnity plan were far less likely to be covered for palliative pain and symptom management than those in a managed care plan.

Palliative care. The goal of palliative care is to relieve suffering, control symptoms, and restore functional capacity in the context of personal values and beliefs. Palliative care can complement other therapies appropriate to the goals of care. Care interventions may increase in frequency and intensity as the illness progresses. The priority of care frequently shifts to focus on the dying process. Palliative care guides patients and families as they make the transition through the changing goals of care. While palliative care has become a specialty within health care

disciplines, the fundamental concept of palliation should be part of the practice skills of all clinicians.¹⁴

In Michigan, there are 44 hospice or palliative care units in community hospitals and 28 physicians certified in palliative care. In 1996, the federal Health Care Financing Administration (HCFA) approved a new diagnostic code for palliative care that enables coders reviewing hospital charts to indicate that palliative care was delivered to a dying patient during a hospital stay. These data will allow HCFA to analyze payments for end-of-life care with the possibility of creating a special diagnosis-related group for people who require hospitalization close to the end of their lives.¹⁵

According to the Commission's survey, the range of palliative care services covered by plans included pain and symptom management, acute dying, and respite care. Most beneficiaries were covered for palliative acute dying care and almost a third were covered for pain and symptom management, but few were covered for respite care.

Survey overview and analysis.

Survey design. The survey questionnaire is presented in its entirety in Appendix D of this report. It was comprised four parts. Part 1 asked about the company name, the type of coverage provided (e.g., indemnity, managed care), and the number of covered lives under various plans offered. Part 2 asked about coverage for hospice services. Part 3 asked about coverage for palliative care. Part 4 asked about coverage for other end-of-life services. Survey participants were not questioned about reimbursement rates.

The survey instrument was developed and analyzed by Roberts Research Associates in consultation with the work group chair, work group members, and the Commission staff. In addition, the work group sought and received advice from several organizations including, but not limited to, researchers in the area of health benefits, providers of end-of-life care, insurance providers, and state officials.

Survey sample and distribution. The Division of Insurance, on behalf of the Commission, distributed the survey to the 25 largest insurers and MCOs that provide the majority of health care coverage in Michigan. Survey participants provided insurance or health care coverage through three types of providers: indemnity, TPAs, or MCOs. Participation in the survey was voluntary. Both the Division of Insurance and MDCH provided follow-up with insurers and MCOs to increase the survey response rate.

Returns and computation methodology. Out of the 25 surveys mailed, a total of 10 insurers and MCOs completed the survey, providing information about 20 different health insurance plans. Although the response rate was lower than desired, responses were received from the largest insurers and MCOs in Michigan. Plans that covered only Medicaid-eligible people or did not provide basic health benefits (e.g., supplemental coverage only) were not included in the final analysis.

The survey analysis in this report is based on 12 plans described by the 10 participants. According to the survey responses, these 12 plans covered a total of 6,114,840 lives. Total

covered lives may include duplication — i.e., some people may be counted twice because they have two policies. Where appropriate, the survey results are reported not by number of insurers or MCOs reporting but by number of covered lives. Since the number of lives covered by these insurers and MCOs varies from 41,000 to more than 4 million, the number or percentage of people covered for each type of benefit is more informative than the number or percentage of insurers and MCOS in the sample who provided the coverage.

Limitations. The survey was limited in several ways, and its results should be viewed only as a tool that, in conjunction with other tools and information gathered by the Commission, can guide and inform discussion on health insurance coverage and end-of-life care. The limitations include:

- The sampling method of the survey does not allow for results to be generalized to all insurers, MCOs, coverage plans, or the general population.
- The survey uses secondary data sources (e.g., administrative data) and is subject to the usual types of errors associated with these data, including coding errors and generalized counts.
- No analysis was done to assess potential non-response bias. For example, insurers that limit coverage or have no hospice coverage at all may be less likely to respond.
- No follow-up was done for non-answers included in responses. For instance, one responder provided “yes” or “no” answers to all coverage questions on pain and symptom management services except for the coverage of opioid medications. Therefore, no determination can be made if opioid medications are covered for some 140,000 covered lives. This type of non-response skews the estimates because numerous covered lives are excluded from the calculation.
- No weighting or statistical tests were applied to the data obtained from the questionnaire (survey estimates are simple percentages). Calculating a standard error would determine a range in which the true number may fall and make the final estimates more reliable. In addition, a standard error could be used to tell if the difference between estimates is statistically significant.
- No stringent comparison of survey responses to actual health insurance policies was done to verify accuracy of responses.
- The delineation of covered lives by provider type or lack of definitions can invalidate comparison between indemnity and managed care plans and affect the estimates made. For instance, some responders marked both indemnity (fee-for-service) and managed care plans for type of coverage provided, but did not delineate number of covered lives for each. With a lack of definitions, aggregated data from the various responders may be compromised due to how broadly responders defined and categorized services.
- Covered lives in the survey were not an unduplicated count, which limits analysis.
- No analysis was done to determine the geographic distribution of covered lives identified by responders. It is not known whether the covered lives identified in the survey are distributed throughout the state. For instance, the majority of covered lives could be heavily weighted toward Southeastern Michigan.

Given these limitations, interpretation of the data presented in this section must be measured against the information presented in the Commission’s more comprehensive final report. The survey instrument did have the virtue of being limited in the number and types of questions. It was not complex, and it relied upon administrative data that were readily available to most responders. Also, it was piloted to refine sequence and phrasing of questions.

Description of respondents. Of the 10 respondents to the survey, seven were MCOs and three were indemnity insurers or TPAs. One respondent identified itself as both an MCO and indemnity insurer but was placed in the MCO category because most of its beneficiaries were HMO members. One of the indemnity insurers covered hospital care only.

Although more MCOs responded to the survey, they represented only 30 percent of the covered lives, while indemnity plans or TPAs covered the other 70 percent. The largest insurer responding was an indemnity/TPA insurer with more than 4 million beneficiaries, or more than two-thirds (67 percent) of the covered lives reported. Of the MCO-covered lives, one MCO covered 31 percent of the beneficiaries.

Hospice benefits and reimbursement (including pain management).

Eight (67 percent) of the plans reported providing hospice coverage: two indemnity plans and six MCOs. The hospital-only indemnity plan and an individual policy plan (not a group plan among the indemnity insurers) reported they provided no hospice coverage. One MCO, actually a network of several HMOs, reported two plans without hospice coverage. Although the overall policy for the network of HMOs does not provide for hospice coverage, one or two of the individual HMOs within the network do have contracts with hospice organizations. Another in the network indicated that it sometimes contracts with a hospice organization on a case-by-case basis when requested and approved for each beneficiary.

Of the eight plans, a total of 4.2 million people had hospice benefits: more than 2.9 million of the covered lives had coverage through an indemnity or TPA plan, and nearly 1.3 million received coverage through an MCO plan (See Table VIII(E).1). Six of the eight plans with hospice benefits reported the number of hospice patients during 1999, totaling 1,542 hospice patients or 4.2 for every 10,000 covered lives.

Seven of the eight plans with hospice benefits reported that the average employer's premium costs per month included hospice care in their plan. Only two reported any additional costs for hospice coverage, at an additional 15 and 23 cents per month for family coverage.

Indemnity/TPA plans. Both indemnity plans set a maximum dollar limit for their hospice benefit; one plan (99.4 percent of the indemnity covered lives) had a \$15,313 limit and the other (0.6 percent of the covered lives) \$7,500. Each also limited the maximum number of days, varying between 210 and 200 days respectively. The larger plan responded that the maximum dollar or days limit could be increased where necessary. Neither plan required pre-certification or authorization for hospice care, but curative benefits were reduced when hospice was chosen. The smaller plan required a variable deductible depending on the employer group. Neither plan required a co-pay if hospice was received from a member of its provider network, but the larger plan required a \$100 co-pay if hospice was outside the network.

The larger indemnity plan paid for hospice services on a per diem basis, with the rates varying by intensity of care. Capitated (per diem) rates did vary by intensity of care. The smaller plan paid for hospice services on a per-service basis. Table VIII(E).1 illustrates indemnity/TPA coverage reimbursement standards.

MCO plans. None of the MCOs reported a dollar limit for hospice care, and 42.3 percent of MCO-covered lives had no maximum on days of hospice care. The remaining MCOs placed either a 180-day limit (17.3 percent of the MCO-covered lives) or a 210-day limit (40.4 percent of the covered lives). None of the MCOs allowed its maximum limits to be increased. All required pre-certification or authorization for hospice care but did not reduce curative benefits when hospice care was chosen. Only one MCO (2.7 percent of the covered lives) required a co-pay for hospice care, and one MCO (12.5 percent of the covered lives) required co-pay when the beneficiary used a provider within the network.

More than half (54.0 percent) of MCO-covered lives had coverage that reimbursed providers for hospice services on a per diem basis. The remaining MCO-covered lives had coverage that reimbursed using some combination of a per diem and a per service basis, depending on the service or the group plan. Most reimbursement did not vary by the intensity of care. Table VIII(E).1 illustrates MCO coverage reimbursement standards.

Hospice summary. Overall, 69.4 percent of people had a maximum dollar limit and 87 percent had a maximum day limit on hospice care. For 71.9 percent of the covered lives, the maximum on both these limits could be increased. The benefit for 30.6 percent of the covered lives required pre-certification or authorization for hospice care, and 69.4 percent had curative benefits reduced when hospice was chosen. Only 1.2 percent of the covered lives were required to pay a deductible, and only 3.8 percent required a co-pay if the hospice provider was within the plan's network of providers. More than 85 percent of covered lives had plans that paid hospice benefits on a per diem basis, the others paid per service or varied payment by type of benefit or group plan. For most covered lives (72.6 percent), these benefit payments varied by intensity of care.

Both indemnity plans offered Medicare supplemental insurance, but only the larger one included hospice benefits as part of that insurance. Three of the MCOs, representing slightly more than half the covered lives, offered Medicare supplemental insurance that included hospice benefits. Table VIII(E).1 illustrates total coverage reimbursement standards.

Services. All but one plan covered all specified hospice sites; the remaining plan covered all but inpatient hospital, and according to survey responses, there was slight variation in coverage with regard to hospice services. The smaller indemnity plan did not cover homemaker or case management services, while most MCOs covered all services except homemaker. One MCO (17.3 percent of the MCO-covered lives) indicated coverage for selected services (i.e., professional nursing, individual counseling, durable medical equipment, drugs, physical therapy, and case management) was provided elsewhere in the plan.

Table VIII(E).1: Hospice Reimbursement.

	Indemnity/TPA	MCO/HMO	Total
Number of covered lives	2,918,863	1,287,810	4,206,673
Percent of covered lives with hospice care that have the following coverage:			
Maximum dollar limit	100.0%	0.0%	69.4%
Maximum care day limit	100.0%	57.7%	87.0%
Maximums can be increased	99.4%	0.0%	71.9%

Prior authorization required	0.0%	100.0%	30.6%
Curative benefits reduced	100.0%	0.0%	69.2%
Deductible may be required	0.6%	2.7%	1.2%
Co-pay may be required	0.0%	12.5%	3.8%
Reimburse per diem	99.4%	54.0%	85.5%
Reimburse per service	0.6%	0.0%	0.4%
Reimbursement varies	0.0%	46.0%	14.1%
Capitated rates vary by intensity of care	100.0%	10.9%	72.6%

All plans except for the small indemnity plan responded that they used case finding or case management to identify individuals who might benefit from hospice. No plans provided patient or physician educational materials on the benefit, purpose, or use of hospice. Table VIII(E).2 illustrates coverage for hospice sites and services.

Table VIII(E).2: Hospice Benefits: Covered Sites and Services.

	Indemnity/TPA	MCO/HMO	Total
Percent of covered lives with hospice care that covers the following settings:			
Hospital	99%	100%	100%
In-patient facility (stand-alone)	100%	100%	100%
Nursing or extended care facility	100%	100%	100%
In-home	100%	100%	100%
Percent of covered lives with hospice care that covers the following services:			
Professional home nursing	100%	100%	100%
Homemaker	99%	3%	70%
Home health aide	100%	72%	91%
Individual counseling	100%	100%	100%
Family/bereavement counseling	100%	100%	100%
Durable medical equipment	100%	100%	100%
Drugs	100%	100%	100%
Physical and other therapies	100%	100%	100%

Palliative care benefits and reimbursement (including pain management).

Two of the four indemnity plans that provided hospital coverage responded that they reimbursed hospital admissions for palliative care. However, these two accounted for only 1.4 percent of indemnity-covered lives. Five out of nine MCOs (55.3 percent of MCO-covered lives) reimbursed for this service.

Only one small indemnity company reimbursed for palliative care consultations (0.4 percent of indemnity-covered lives), but 64.6 percent of MCO-covered lives had coverage that reimbursed providers for all palliative care consultations and 33.3 percent were reimbursed for physician consultations only.

Table VIII(E).3 illustrates coverage by indemnity/TPA and MCO care for hospital reimbursement of symptom management, acute dying, and respite care.

Table VIII(E).3: People Covered for Three Types of Palliative Care.

	Indemnity/TPA	MCO/HMO	Total
Percent of covered lives with specific hospital reimbursement for:			
Pain and symptom management	1.4%	98.0%	29.5%
Acute dying	100.0%	75.7%	92.9%
Respite care	1.0%	12.1%	4.2%

Other end-of-life care benefits.

Pharmacy coverage. Outpatient pharmacy coverage is a benefit in all plans but one. This indemnity plan generally offers pharmacy coverage as a rider (supplemental coverage at

additional expense). However, many groups that are part of the plan do not actually receive pharmacy coverage. This is a particular problem in pain management when hospice care is not used or drugs are not covered.

Non-hospice care. There was little variation in coverage for non-hospice end-of-life care. Both indemnity/TPA plans and MCOs covered all services except in some cases for counseling and acupuncture. The indemnity plans covered all personal counseling and all acupuncture, but did not cover bereavement counseling for the family. Four MCO plans (40 percent of MCO-covered lives) covered counseling for the patient and for the family. Only one MCO plan (10.3 percent of covered lives) covered acupuncture. Table VIII(E).4 illustrates coverage for non-hospice care.

Care management. All indemnity and MCO plans responded that they paid for a care manager to coordinate care at the end of life (e.g., help make the transition between hospital, nursing home, and hospice care).

Specialist providers. The survey asked MCOs if they had service agreements for three types of specialist providers. Six MCOs (83.6 percent of the MCO-covered lives) responded that they had a service agreement with a pain management center. All seven MCO plans responded that they had an agreement with a hospice provider. The largest MCO added, "While [it] is not contracted with any particular hospice, it has access to any BCBSM participating provider." Three MCOs (55.4 percent of the covered lives) have service agreements with a palliative care specialist.

Table VIII(E).4: Coverage for Other End-of-Life Care.

	Indemnity/TPA	MCO/HMO	Total
Percent of covered lives with specific coverage outside of hospice:			
Opioid medications	100%	100%	100.0%
Chemotherapy	100%	100%	100.0%
Radiotherapy	100%	100%	100.0%
Nerve block techniques	100%	100%	100.0%
Implantable pumps	100%	100%	100.0%
Durable medical goods such as pumps and tubing for IV infusion systems	100%	100%	100.0%
Central venous catheterization as access for infusion therapy	100%	100%	100.0%
Pain management clinic costs	100%	100%	100.0%
Psychosocial counseling for patient	100.0%	40.1%	85.3%
Bereavement counseling for family	0.0%	40.1%	9.9%
Acupuncture	100.0%	10.3%	77.9%

One or more of the plans identified the following limits on end-of-life care:

- Limited number of visits per year for some services/programs.
- Providers reimbursed according to negotiated fee schedules.
- Co-payments may apply.
- Services payable only if related to treatment of a condition/procedure.
- Lifetime maximum under policy is subject to medical necessity, not experimental-investigational interests.

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