

August 2001

The Honorable John Engler
Governor, State of Michigan
Lansing, Michigan

Dear 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 is a summary version of the Commission's recommended model state and institutional policies for end-of-life care and 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. A full-text version of this report, along with the rationale for each recommendation and supporting documentation, will be delivered to you under separate cover this fall. State officials, legislators and other interested parties may access that full 175-page report on the web.

The Commission was also charged with producing an inventory of existing resources available to Michigan citizens for end-of-life planning. That inventory will be published in the form of a resource guide for end-of-life care 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. Our work is not the final word on any of these topics but represents a significant step toward improving end-of-life care for all in our state; it is actually a discussion of issues to be addressed. We have, however, read widely and listened carefully, and we know that, working together, we have the power to make the last phase of life better for Michigan's patients, families, clinicians, and communities.

Sincerely,

Rev. Clayton L. Thomason, JD, MDiv
Chair

Michigan Commission on End of Life Care

Contents

| | | |
|-------|--|----|
| I. | Executive summary of recommendations _____ | 1 |
| II. | Background of the Commission _____ | 5 |
| III. | National overview _____ | 7 |
| IV. | End-of-life care in Michigan _____ | 11 |
| V. | Committee reports and recommendations | |
| | A. Professional education _____ | 17 |
| | B. Pain and symptom management _____ | 21 |
| | C. Reimbursement _____ | 25 |
| | D. Long-term care _____ | 29 |
| | E. Decision-making for the end of life _____ | 31 |
| | F. Family issues _____ | 35 |
| VI. | Bibliography _____ | 39 |
| VII. | Glossary _____ | 45 |
| VIII. | Appendices | |
| | A. Executive Orders _____ | 51 |
| | B. Survey on private health insurance coverage _____ | 55 |
| | C. Barriers to end-of-life care _____ | 65 |

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 barriers are summarized in Appendix 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 17 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 21 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 25 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 29 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 31 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 35 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.)

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 the 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 Coalition in the Department of Community Health and the Advisory Committee on Pain and Symptom Management in the 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 end-of-life 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 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 of these resources for the general public.

Commission procedures.

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

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 five public hearings and several group presentations. The Commission also gathered data through surveys on insurance, undergraduate health-care education, graduate medical education, continuing medical education, and the Michigan OPP.

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, and for background information and staff support received from MDCH and MDCIS, and to the numerous other individuals who generously gave their time and expertise to this project.

End-of-life education and outreach.

The Commission report will 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 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 for you 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.

III. National overview.

Issue: 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 reliance of the health care industry on managed care 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 but 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 these measures are 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). The results of this study were remarkable because it showed that intense interventions had virtually no effect on any of five key 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 data showed that most individuals died in the ICU, without consideration for their choice of care options and often in moderate to severe pain.

Although some parts of this landmark study were debated, it became a siren call for new approaches to care at the end of life. Since the SUPPORT study, commissions or task forces have been established in approximately half the states to examine end-of-life issues; most have recommended better pain management by physicians, better use of advance directives, and ways to overcome financial and other barriers to improving end-of-life care services.

Analysis.

The following overview of what has been accomplished, and what remains to be accomplished, in end-of-life care nationwide is 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.

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." An additional study, also funded by the Robert Wood Johnson

Foundation, had similar findings for nursing education programs across the country and 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 in 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

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 Florida, Michigan, Oregon, Texas, California, and other states are attempting 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 have begun to address these concerns through changes in statutes and regulations, development of medical licensing board guidelines, and workshops for medical boards and providers. More than a third of the states now have statutes that specifically allow physicians to prescribe controlled substances to relieve pain. Despite these efforts and actions by some federal agencies and private organizations, regulations and guidelines still vary widely from state to state, and a huge amount of work remains to be done before there is anything like uniformity to this nationwide patchwork of policy and practice in end-of-life care.

Financing. A large proportion of all payment for end-of-life health care and other services now comes from Medicare and Medicaid, but fewer than 20 percent of Medicare patients use the Medicare hospice benefit, and then only for the last month or so of life. Little is known about financing end-of-life care for people less than 65 years old. Service is often fragmented. Aside from hospice care, few medical services target care for patients at the end-of-life; instead, these patients usually use services, such as prescription drugs, inpatient hospital care, durable medical equipment, and home health care, that are also available to those who are not terminally ill. Many needed services are not covered by health insurance, and data indicates that the out-of-pocket expenses for dying individuals’ care frequently 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.”

Nationally, many believe that barriers to good end-of-life services are unique to hospice care. They include arbitrary eligibility criteria (principally the six-month hospice rule), a Medicare rule that 80 percent of hospice

services be provided in the home, reimbursement that is not based on actual costs of delivering care, and cultural attitudes that delay moving from curative therapies toward end-of-life care options.

Advance directives. All states recognize some form of end-of-life and surrogate decision-making. Even though all have statutes that allow for appointment of a surrogate, such as those for durable power of attorney, their 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 an advance care plan at the time of death. Unfortunately, even these are frequently too general to provide a meaningful direction and often are not applicable to the clinical circumstances of the person's dying. Those 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 forms to communicate these choices to health care providers.

IV. End-of-life care in Michigan.

Issue: The urgency that faces Michigan's public and private organizations as they seek to develop more effective and compassionate end-of-life services is heightened by the emergence of an older population that will grow dramatically in the coming decades, will live longer, and will require more in the way of services — even as the segment of the population that traditionally includes caregivers shrinks.

Background.

Three-quarters of the people who die in Michigan each year are 65 or older, and about one-third of all Michigan deaths are women age 75 and older. 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, are healthier than previous generations, and can expect a long life.

There will also be significant shifts within age groups over the next 30 years. The traditional caregiver group (ages 20-54) will shrink as a proportion of the total population, while the cohorts of those 55 years old and older, 65 and older, and 85 and older will continue to swell. As soon as 2020, people older than 75 will make up the largest age group of the population. The economic and health care implications of these demographic trends are clear.

The causes of death are also changing, from contagious diseases to chronic conditions such as heart disease, cancer, stroke, chronic obstructive pulmonary disease and allied conditions, unintentional injuries, pneumonia and influenza, and diabetes mellitus. Medical treatments make it possible to live with these diseases, but the care is often intensive, prolonged, and, hence, costly. It is also difficult to determine when patients with most of these diagnoses are terminally ill.

Where death occurs. Each year about one percent of any population group will die. In Michigan in 1998, 84,906 people died. In general, people in Michigan and in the nation die in one of three locations. In 1998, 47 percent of the Michigan residents who died (40,466) were in a hospital; 23 percent (19,695) were residents in nursing homes; and 26 percent (21,816) were at home. The remaining deaths (fewer than 5 percent) occurred in an ambulance, other institutions or places, or in unknown locations. Compared with 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 there are fewer deaths in Michigan in hospitals and more at home and in nursing homes. 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. It may also indicate a deterioration of service if it reflects attempts to limit costly inpatient hospital lengths of stay and comes at the cost of additional burden to the informal caregiver and the household for services previously rendered by health-care providers.

Settings in which services are delivered.

Acute care. As the world's thinking about end-of-life care has evolved, some end-of-life services have moved out of the acute-care (hospital) setting into separate hospice programs, other facilities, and patients' homes. However, since nearly half of Michigan citizens are still dying in hospitals, the need for comprehensive end-of-life services in the acute-care setting is as real as ever. Some hospitals have responded with 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 about patients’ wishes for their care.

Detroit Receiving Hospital uses a therapeutic intervention symptom severity (TISS) scoring system as a model for determining care for a select group of patients in the ICU. 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 receives during a hospital stay. The program targets the patient admitted with an acute illness or injury who is not expected to survive hospitalization, but any patient with any diagnosis has access to it. The TISS system 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.

Both the Oakwood and Detroit Receiving Hospital programs have shown better patient satisfaction and family satisfaction with the treatments given to their loved ones at the end of life. They have also demonstrated that it is possible to achieve this while reducing or redistributing costs over the course of patient care — and without increasing risk-adjusted mortality.

Long-term care. Long-term care is a broad term that is applied to a variety of populations, services, and funding sources. 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 other dementias, and individuals who are at the end of life. Long-term care participants can also be defined as people who receive hands-on help, supervision, or standby help with activities of daily living or activities that result from a health condition.

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 home, assisted living facilities), it is important to understand long-term care services more broadly. Long-term care can be described as an array of settings and services that include the 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.

Under federal law, long-term care services for individuals who qualify 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 MDCH also 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. MDCH defines 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, Medicaid pays for 70 percent of all nursing facility care, while Medicare pays for about 10 percent.

Long-term care is recognized as a major policy issue because of the scope of the programs it includes and because of the demographic predictions of the continued growth of the long-term care populations (as previously discussed). This group is also becoming more racially and ethnically diverse. This will no doubt have implications for the delivery of long-term care services that will require, for example, skilled palliative care clinicians and increased cultural competence among service professionals.

MI Choice. In 1992, Michigan received approval from the federal Health Care Financing Administration (HCFA) to implement the Home and Community Based Services for the Elderly and Disabled waiver program, now also known as the 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 and who reside in their own home or other residential setting in their community. In 1998, MI Choice became available in all Michigan counties. MDCH contracts with over 20 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 many participants are enrolled after a hospitalization.

Michigan studied the importance of end-of-life issues for MI Choice participants in 1997-98, resulting in Medicaid policy changes that allowed access to hospice care. Michigan is the only state currently allowing such access. In 2000, 289 MI Choice participants statewide also received hospice care.

Hospice programs. Hospice care is now more widely available in Michigan than ever before. The Michigan Hospice and Palliative Care Organization 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. 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.

Although hospice services may be available to Michigan citizens, they are currently not widely used. Hospice services are often misunderstood by health care providers, patients, and the community in general. 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 their 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.

Palliative care for children. Comprehensive health services for children with limited life expectancy due to illness are currently not 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.

Yet, 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 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.

There are no comprehensive pediatric palliative care services in Michigan. In a few locations, inpatient hospital care is provided for patients who are actively dying, along with symptom management and respite for significant family stress. Palliative care consultation is available in three of Michigan's large tertiary children's hospital programs (not always provided by pediatric specialists), and two Michigan pediatric physicians have completed certification in palliative care.

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

Home care. Home care providers deliver health care and supportive services ranging from 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 to refer to palliative care or hospice specialists who can provide intense symptom management, supportive end-of-life care and assistance with life closure, while some of these patients could also benefit from minimal restorative care although cure is no longer an outcome.

Public and private initiatives.

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.

MDCH has facilitated and supported a variety of efforts to position Michigan as a leader in end-of-life care. These include:

- Michigan Circle of Life. Formed in 1997, this coalition of professional associations, organizations of care providers, education, religion, and advocacy groups, and others focuses on preserving the dignity and rights of terminally ill and chronically ill people in Michigan.
- A toll-free public information phone line that provides information and education about hospice and end-of-life care to the general public and providers.
- The Michigan Partnership for the Advancement of End of Life Care, which in 2000 received a three-year, \$450,000 grant from the Robert Wood Johnson Foundation to research three key areas of end-of-life care: health professional education, nursing facilities and community resources.
- CD-ROM interactive series on pain management and end-of-life care.
- The Long-Term Care Work Group, which 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 facilities of the future, and organized systems of care.
- Legislative actions dealing with patient rights and protections, pain management, and health care decision-making.

In addition, MDCIS:

- Assures standards are met through licensing and inspecting facilities and providers such as hospitals, hospice programs, nursing facilities and individual providers
- Works with the Michigan Hospice and Palliative Care Organization to encourage appropriate pain management in end-of-life care
- Through the Quality Improvement Nurse Consultation Program, is developing educational programs to promote best practices in long-term care facilities related to pain management and other end-of-life services
- Serves as a resource to hospice programs for information on medications and pain management

Private organizations. The Michigan Hospice and Palliative Care Organization serves 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 organization represents more than 90 hospice programs throughout the state 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 organization is supported by hospice programs, physicians, business organizations, and individuals who believe in its work.

In 1998, the Michigan Health and Hospital Association created a Task Force on End-of-Life Care, with subcommittees on professional issues; patient, family and community issues; and regulatory, legislative and reimbursement issues. The group made a number of recommendations for improvements in end-of-life care that were subsequently approved by the association's board.

The Michigan State Medical Society, an association of 14,500 medical doctors licensed in Michigan, has been actively involved in end-of-life issues for decades, and in 2000 the society 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, is being distributed to Michigan physicians.

V (A). Professional education.

Issue. Access to effective end-of-life care requires health care professionals who are educated to deliver it. How can we assure that appropriate instruction is provided and absorbed, both during formal education and afterward?

Background.

Henry Ford Health System, based in Detroit, has one of only four endowed chairs in North America for the study and promotion of end-of-life care (the others are in New York, Montreal, and Cleveland). And yet, while efforts are under way in some Michigan medical and nursing schools to educate students in the basic elements of palliative care, comprehensive end-of-life care curricula are the exception. The Commission's professional education work group sought to evaluate the adequacy of professional education in Michigan health professional education, residency instruction, and continuing education programs. The Commission undertook a survey of Michigan medical residency programs, 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. Results are preliminary but will be part of a comprehensive final report released by the Partnership in 2003.

Analysis.

According to a 1998 survey by the American Association of Medical Colleges, fewer than 40 percent of medical schools offer an elective course that deals with palliative care, and fewer still have required such a course. 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. The association's Medical School Objective Project sets out national educational standards and objectives for end-of-life curricula.

An effort with similar objectives is under way in Michigan, called the Michigan Partnership for the Advancement of End of Life Care, funded by the Robert Wood Johnson Foundation. It has undertaken an evaluation of the state of professional education among Michigan schools of medicine, nursing, pharmacy, social work, and pastoral care. Its findings to date indicate that significant efforts are under way to develop and implement innovative and effective end-of-life curricula in Michigan's health professional schools and education programs.

Medical education. Michigan's four colleges of medicine (at the University of Michigan, Wayne State University, and the Colleges of Human and 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 courses in end-of-life care issues. Through the development of core competencies in pain and symptom management, palliative care, and patient and family issues, as well as attention to the organization of care, 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 have a breadth of experience, knowledge, and skills related to end-of-life care. 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 to provide high-quality end-of-life care to patients and families. The 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 in the required curriculum. 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 explicitly addressing 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 program directors in these programs said they felt that inadequate attention is given to end-of-life care curriculum.

Postgraduate education. Evidence suggests that experience in a medical residency is an important stage of professional education since it is a formative period for clinical identity. Finding a lack of reliable data regarding postgraduate medical education, the Commission undertook a comprehensive survey of residency and fellowship programs in Michigan. The Commission's 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 through a mail survey of 275 residency and fellowship directors. The survey revealed that fewer than one-third (30.7 percent) of the 192 respondents had any formal instruction in hospice care. Less than half (45.8 percent) reported formal instruction in end-of-life care, while slightly more (55.7 percent) reported formal education in pain management. Primary care programs appear to devote significantly more time on end-of-life education than other areas. The actual survey instrument, and more detailed analysis and conclusions, will be a part of the full-text version of the Commission Final Report, released under separate cover. Future studies must assess postgraduate preparation more rigorously than is possible in a self-report study.

Recommendations.

Recommendations for the undergraduate, graduate, and continuing education of those engaged in the delivery of health care and related services in Michigan include:

1. Health professional schools or programs should include in their core curricula the standard content of end-of-life care appropriate to each discipline, including knowledge, skills, and attitudes. They should regularly assess and evaluate end-of-life care content, both didactic and experiential, in their curricula, including 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 education 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. 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 end-of-life education.
5. MDCH should explore possibilities for making financial grants available to students enrolled in health professional schools or programs that are committed to end-of-life care.

6. MDCH, MDCIS, and all applicable health profession licensing boards should promote and advance the art and science of end-of-life care in the 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 its finding that the current model of didactic lecture-based continuing medical education is not effective in changing the behavior of practicing physicians, 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 relicensure accordingly.

V(B). Pain and symptom management.

Issue: Michigan citizens endure unnecessary suffering at the end of life. What methods can be used to eliminate this and other burdens and improve end-of-life care?

Background.

This committee studied the ability of individuals in Michigan to obtain effective pain and symptom management as an essential part of high-quality end-of-life care. This report covers consumer, professional, institutional, and distribution issues and the effect of applicable regulatory programs on access to effective pain and symptom management.

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.

Michigan citizens deserve good pain management. Experts agree and data indicate 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 health professionals assume. Vigilant attention to physical and emotional symptoms is the core of high-quality end-of-life care.

Analysis.

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. This report is not intended to diminish their importance in pain management, but the committee focuses its comments on the opioid analgesics because they are the single most effective and underutilized class of medication for the treatment of pain at the end of life.

The Federal Controlled Substances Act and the Michigan Public Health Code both intend to provide a balanced approach to controlled-substance medications 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 such balance. Michigan needs a 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. Michigan's 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.

Recommendations.

The recommendations of the committee are found in their entirety on pages 2 and 3 of this report, in the Executive Summary. The committee contemplated its recommendations with the needs of each of their loved ones in mind, as well as their individual needs. The committee has recommended changes in regulations with an agency focus that it believes will significantly improve pain care for Michigan citizens, and is confident that these improvements will allow the people of Michigan to experience the end of their lives in comfort. The committee believes that all the recommended changes are value added in that they require no additional outlay of resources by public or private agencies but rather a realignment of current resources for education, regulation, health promotion, and clinical care.

The first and most important of these recommendations stems from the widespread finding that lack of effective pain and symptom relief is a public health issue that requires the highest level of professional and regulatory attention. The science of pain management has progressed to the point where it is always possible to reduce pain to levels that are acceptable and tolerated by patients. Yet Michigan citizens have very low expectations about having their need for pain relief met, and the current health care system does little to disprove them. (This appears as General recommendation #1 in the “Executive summary of recommendations.”)

The committee recommends ways in which information about available therapies can be better disseminated to both the public and health professionals. New requirements for pain assessment, treatment, and acceptability by patients are being implemented by national and state entities. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) now requires that hospitals seeking accreditation assess patients for pain, identify the level of pain, and demonstrate effective and acceptable treatment of that pain, all on an individualized basis and in a timely manner. In its first recommendation, the committee supports institution of unit- and service- specific education so that patients in their unique settings and with their unique clinical circumstances can have their pain managed by knowledgeable, competent, well-educated health professionals.

To help their licensees maintain a high standard of practice in pain care, Michigan health profession licensing boards should adopt guidelines and change them as the science of pain management advances. An example of work that has been done recently in this area is the “Model Guidelines for the Use of Controlled Substances for the Treatment of Pain”, from the Federation of State Medical Boards. Rules and expectations for meeting their patients’ pain needs should become standards of quality health service, so that variations from the high standards become bases for disciplinary action. (Recommendations #2-3)

Language in Michigan statutes should be changed to identify each patient’s right to information and treatment options for management of pain and symptoms whether or not the patient’s condition is terminal, and regardless of whether the goals of that patient’s treatment are curative, palliative or both. (Recommendations #4-5)

The committee believes that some policies and programs impair the delivery of quality pain care for Michigan citizens. Chief among these is the OPP, which perpetuates an unbalanced systemic approach to the use of opioids as controlled substances in Michigan. The rules and regulations promulgated by the OPP impair Michigan citizens’ access to effective pain management without providing the intended corresponding benefit of controlling the diversion of prescription drugs for inappropriate non-medical use. The committee found many examples of the difficulties involving the current OPP among prescribers, patients, health systems, and the community.

Administration of the OPP costs approximately \$750,000 annually, and in 2000, the program reconciled more than 600,000 prescriptions of Schedule II drugs, mostly opioids, some stimulant medications, and a few other drugs. During that year, more than 192,000 physicians, nurses, and dentists cared for the state’s pain-relief needs, yet only eight cases of prescription drug diversion occurred in the state. During the same period, fewer than one-third of the state’s most severely ill and dying patients (those being admitted to hospice programs) presented with their pain adequately managed. The committee determined that the OPP has not had a sufficiently measurable effect on prevention of drug diversion to justify the adverse effect it has on the ability of patients to obtain effective pain and symptom management in Michigan.

The committee surveyed attitudes of Michigan physicians about the OPP. Almost 40 percent of respondents stated that they feared regulatory scrutiny if they prescribed Schedule II drugs, and some comments by anonymous respondents reflected that they prescribe drugs on other schedules, even when they are known to be less effective or could have serious side effects on the gastric system or kidneys. This is often referred to as the “chilling effect” of programs such as the OPP in which physicians’ willingness to comply with the various requirements of the program is decreased. The actual survey instrument, complete analysis and conclusions will be a part of the full-text version of the Commission final report, released under separate cover.

Michigan needs a system that both limits drug diversion and promotes high-quality pain care. The committee recommends repealing the OPP in its current form and replacing it with a system that supports electronic monitoring of the prescribing of a wide variety of medications (including Schedule II and Schedule III opioids). The new system should be developed with the advice of pain management experts and law enforcement so that it will capture the data needed by both. It should require no special prescription form; it should be efficient and invisible to the patient and practitioner; and it should provide information that is well understood and available to all those who need it. Some models of other states' monitoring programs are identified in the committee report that will be a part of the full-text version of the Commission final report, released under separate cover. (Recommendations #7-8)

All the regulatory challenges to good pain and symptom management do not lie within the Michigan Legislature's or the Governor's sphere of influence. The federal government has imposed well intended but problematic statutes that impede effective pain management. The committee supports working with the Michigan Congressional delegation to remove these barriers, including lifting the restrictions on obtaining prescription refills, broadening the circumstances under which phone orders are permitted, and eliminating prohibitions on electronic transfer of prescriptions for Schedule II medications. (Recommendation #9)

The ability of Michigan's pharmacies to supply adequate volumes of these prescription medications is important. The committee recommends that the Board of Pharmacy monitor Michigan's supply of these medications, and develop a system to ensure that patients and their families can receive an adequate supply when a valid prescription is presented. When pharmacists are not able to dispense these important medications for any reason, they should help patients find the closest available supply. (Recommendation #10)

Health plans and third-party payors should study the reasonable cost of pain management, palliative care consultations, and non-pharmacological treatments of pain and suffering. Although to do so is worthy in its own right, there are data to suggest that when payors require their beneficiaries' pain needs to be met, it results in better health, thus reducing health care costs for the future. (Recommendation #11)

Finally, medical, opioid, and other pharmaceutical products are precious resources. Ways to improve disposition of these unused medications are needed. When there is a central point of control, pharmaceuticals should be retrieved and redistributed for use by other patients with legitimate prescriptions in order to limit waste of medical resources and the attendant costs. Studies of the effect of pharmaceutical waste on the Michigan environment and methods to minimize any detrimental effect must be undertaken. (Recommendation #12)

V(C). Reimbursement.

Issue: What are some practical approaches to reforming the current system for reimbursement of end-of-life care expenses?

Background.

Public monies pay for 80 percent of the costs associated with end-of-life care in America. About 70 percent of those who die each year are covered by Medicare, and about 13 percent are covered by Medicaid, so any discussion of reimbursement for end-of-life care must begin with these programs. Medicare reimburses 32 percent of all hospital costs, 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.

While extensive data quantify the costs of caring for severely ill individuals with unknown life expectancy, there is little documentation of the costs of care delivered in anticipation of impending death. This documentation is needed because the number of people who choose hospice care at the end of life is increasing.

Looking at all payors, Medicare is the largest for hospice services in the last year of life. Medicaid is the primary payor for nursing home-related services but also covers acute care (hospital) and hospice 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.

Medicare. The Medicare hospice benefit was the first legitimate funding source specifically designed to provide comprehensive care to patients with life-limiting illness and their families. Medicare has 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.

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. In its hospice benefit, Medicare covers a wide range of medical services, but it does not cover treatment of a 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.

In 1993, the rates were linked by federal statute to inflation in the cost of goods and services purchased by hospitals nationwide, but they have not kept pace with changes in end-of-life care practices. Medicare hospice reimbursement does not take into account the actual costs associated with current compassionate approaches to caring for the dying and their families, including the costs of new pain-relief medications that have been developed.

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. Another factor in the Medicare hospice rate – hospital wages, are no longer relevant to hospice care.

The original Medicare hospice benefit was based on 70 days of care, but the average length 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.

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. This can result in costs that easily exceed reimbursement at the hospice rate, which is based on conventional-care patients. 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.

One additional issue the commission considered is the federal regulation that restricts the number of inpatient days of care that will be reimbursed to a hospice provider, to no more than 20 percent of the total days of care they provide annually, so that at least 80 percent of care is provided in the home. The policy applies to all hospice providers serving Medicare beneficiaries, and in Michigan, it applies to hospices serving Medicaid patients.

Medicare also reimburses for many 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 services are reimbursed through standard Medicare funding mechanisms.

In addition, Medicare is rarely the only payor for its beneficiaries’ health care needs; many remaining costs are paid through a patchwork of Medicaid, private insurance, out-of-pocket, and other sources.

The six-month rule. Medicare coverage for hospice care generally requires that reimbursement not occur unless two physicians have determined that a person has an 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 statistical curve that resulted has a standard deviation of six months. However, many other illnesses have different disease trajectories, with longer courses and less predictability. For example, 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.

Increasing numbers of palliative care experts call for elimination of the six-month rule. 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 patients and families equate the word “hospice” with “no hope,” and experts feel this is reinforced among some hospices and caregivers.

In addition, nearly half of end-of-life care still is being provided in Michigan’s acute care facilities. Opportunities exist to improve the quality of service in many sites and to realign the current reimbursement methodologies to promote the best service in the proper site according to the goals of care that the patients, and not the system, establish. Only then can we help Michigan citizens complete their lives well and in comfort.

Palliative care. Since the initiation of the hospice benefit in 1982, a body of knowledge and research has begun to develop around end-of-life care precepts. The relief of pain and suffering — comfort care rather than curative care — has been pioneered in the hospice movement but is gaining credibility within mainstream health care.

This type of care, called palliative care, has a developing scientific base to support its interdisciplinary team approach. The root of the word “palliative” is “pallius,” or cloak. Palliative care is a supportive “cloak of services” that protects the patient and family, providing relief from physical, emotional, social, and spiritual suffering. As our population lives longer, there is a rise in the incidence and duration of chronic illnesses. These diseases are not curable and do not fit the reimbursement framework that evolved with the practice of traditional medicine and the health care delivery systems designed to support that framework.

The need for palliative care services earlier than the last six months of life is becoming more apparent, but the reimbursement model does not fit this need. Palliative care experts include an interdisciplinary team of physicians, nurses, social workers, spiritual care counselors, and bereavement counselors, but currently, only physicians and nurse practitioners are able to bill and be reimbursed for palliative care consultations.

Analysis.

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.

A key finding of the literature review was that many physicians are not aware that the system used to bill third-party payors includes codes related to hospice and palliative care, nor do most beneficiaries understand 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 pay for less than 20 percent of end-of-life care, but they still have a major impact on spending of health care dollars. The Commission’s survey findings reiterate the need for consideration of standards for comprehensive end-of-life care benefits, while allowing flexibility for competition and innovation.

Prospects for reform. Since Medicaid reimbursement in Michigan is based on the Medicare model, the hospice benefits and problems of both programs are similar. Michigan indemnity insurance plans and health maintenance organizations, on the other hand, vary in their coverage, so recommendations for reform must address all three of these major streams of hospice reimbursement.

Recommendations for reform must also address the need for palliative care before the last six months of life. This means finding better measures of a patient’s functional status so it is clear if the individual has reached the point that is considered frail versus terminal. Current research defines frailty as the condition in 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, makes frequent visits to the emergency room, and has had more than one hospital stay within six months.

Research has been conducted that demonstrates best practices for the short term, but more research is needed to provide a scientific basis for long-term change in reimbursement methodologies — and achieving real and lasting change clearly requires a systemic approach that can only come from a long-term collaboration among public and private stakeholders.

Recommendations.

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's Office, 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 such as pharmaceuticals, palliative radiation or chemotherapy, durable medical equipment, blood transfusions and products, 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 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
 - 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
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.
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.

V(D). Long-term care.

Issue: How are Michigan's public and private agencies and organizations to keep pace with the end-of-life care needs of the burgeoning population who will be receiving and should benefit from long-term care?

Background.

Several populations need long-term care.

- The elderly (age 65 and older). The elderly are 12 percent of Michigan's population, and the number of people 85 and older (the segment most likely to need long-term care) will triple by 2040. Five percent of all elderly people in the United States live in nursing facilities, and 12 percent live in the community with needs for assistance with activities of daily living such as eating and bathing or with instrumental activities of daily living such as housekeeping and meal preparation. Among those older than 85, 21 percent live in nursing facilities. Forty-nine percent live in the community and have long-term care needs.
- People with disabilities. One of 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 about 10 percent of Michigan's nursing facility residents are younger than 65.
- 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; and for people older than 85, the rate is 16 percent. In Michigan, 250,000 people have Alzheimer's disease or related conditions.
- People at the end of life. In 1998, 84,906 people died in Michigan, and 81,979 of those people lived in one of three settings: hospitals (47 percent), at home (26 percent), and nursing facilities (nearly 20 percent). In 2000, hospice organizations in Michigan reported serving more than 26,000 individuals.

Long-term care in Michigan occurs in a variety of settings. Among the elderly at greatest risk for nursing-facility placement, 86 percent live with others and receive about 60 hours of informal care per week, supplemented by about 14 hours of paid services. More than 80 percent of the elderly with limitations on activities of daily living still live in the community. 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. The Medicaid MI Choice program is designed for people who require a nursing-facility level of care, while the Home Help program generally provides services to individuals with less extensive needs.

National studies indicate that the nursing-facility population is becoming more ill and has more complex needs. Michigan has over 450 nursing facilities serving over 50,000 people who require nursing facility services each year.

Homes for the aged and adult foster care settings provide room and board with varying levels of care. In 2000, there were 4,446 licensed adult foster care homes, with 33,753 beds, and 169 licensed homes for the aged, with 12,818 beds, in Michigan. There also were an estimated 25,000 assisted-living beds in the state. Assisted-living facilities are not regulated in Michigan, so it is difficult to obtain comprehensive information and data on these.

Analysis.

The Committee on Long-Term Care has reached the following conclusions:

- Delivery of pain and symptom management for Michigan residents living with advanced illness in the long-term care setting 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 lack of professional knowledge.

- 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.

Michigan residents of long-term care facilities living with advanced illness or dying deserve quality end-of-life care. Early conversations and documentation regarding advance directives may identify a person's wishes, 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.

Recommendations.

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 quality end-of-life care including:
 - 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
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.
3. 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.
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.
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.
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.

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

Issue: What is the best way for Michigan citizens to make their wishes for end-of-life care known and to be confident that those wishes will be carried out?

Background.

The Final Report of the 1994 Michigan Commission on Death and Dying revealed that an aspect of death Michigan citizens fear is being kept alive by artificial means against their wishes. Michigan law gives every competent adult the right to accept or refuse life-sustaining medical treatment. The right to make one's own decisions about medical treatment is not lost because a competent person becomes incompetent.

The role of advance directives in end-of-life care creates confusion for many persons. The American Bar Association's Commission on Legal Problems of the Elderly, as well as other respected organizations, addresses some of the myths about advance directives. They observe that Americans want the opportunity to recover, if recovery is possible. 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 was no improvement. The difficulty comes in determining when treatment shifts from saving a life to prolonging a death.

There are many factors that add to the complexity of making decisions for health care and communicating those decisions to those who need to know. Some patients worry that physicians would order overly aggressive care to obtain higher reimbursement. Others express concern that they would feel pressure from health-care providers, insurance companies or family to halt medical care in order to reduce costs or burden of their care.

Analysis.

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 Commission's public hearings, 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' perspective, 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.

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 find useful. The one-page, two-sided Physician Orders for Life Sustaining Treatment (POLST) form 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 shocking pink in color, 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).

Elsewhere, a number of instruments are available for addressing end-of-life issues.

- Advance directives. This 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.
- 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.
- Durable Power of Attorney for Health Care. Michigan law recognizes this process for expressing advance directives, and it is also known as the Designation of Patient Advocate. 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.
- 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.

In sum, 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 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. 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 following recommendations.

Recommendations.

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 advocate or otherwise clearly document their wishes.

2. 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 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.
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.
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.
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.

V(F). Family issues.

Issue: Effective, compassionate end-of-life care must go far beyond medical care for the patient to include social, psychosocial, and spiritual support for the patient, the family, and caregivers. How can we effect such services and supporting care in Michigan?

Background.

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 acknowledges 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 also accounts 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.

Analysis.

Efforts to understand and evaluate quality of care at the end of life have led to an evolving understanding of dying as a multi-dimensional experience. Emanuel and Emanuel ("The Promise of a Good Death," in *The Lancet*, 1998) 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, psychological, and cognitive symptoms; social relationships; and economic demands and caregiving needs. The hopes and expectations of the dying person may also be subject to change over the course of the dying process. Finally, the patient's spiritual and existential beliefs often help make sense of the dying experience.
- The potential interventions available to family, friends, health care providers, and others.
- 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. 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 allows for development of a comprehensive, interdisciplinary plan of care for the dying.

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 any plan of care.

Support comes from physicians who coordinate the plan of care and remain in close contact with the family and members of the palliative care or hospice team of providers. It also comes 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. Social workers are counselors to the patient and family, helping them deal with financial, legal, and insurance issues. A religious or spiritual community is an

important source of spiritual, moral, and social support and solace for a family as they cope with the illness and the demands of care giving.

Respite care, in which caregivers are given 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 most 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 significant skilled training 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 after, 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 also 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 relief to the caregivers of the dying.

Bereavement support. Hospice and palliative care programs should be designed to address all the issues of a terminal illness, including the patients' and families' needs during the illness and the survivors' need for support as they proceed through the grieving process of bereavement. After the death of a loved one, it is natural to experience sadness, loss, and grief. Many people feel 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. Instruction in the psychological, social, and spiritual support of patients and their families needs to be part of education in health professional schools, postgraduate education, and continuing education, or it may come from specialized courses such as the program on grief and bereavement available in Madonna University's hospice care education program.

Cultural factors. An individual's cultural identity may be based on heritage as well as individual characteristics, circumstances, and personal choices. Cultural identity may be 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. Personal beliefs and practices, in turn, can influence how patients and health care professionals perceive health and illness and how they interact with each other.

Recommendations.

1. Because the health, finances, and well-being of family members are often threatened as they care for the dying and because they require support to ensure the successful completion of life tasks, MDCH, MDCIS, 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 between life and 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

VI. Bibliography

Published works.

- AARP. Start the conversation: A guide to end-of-life care — in search of a good death. *Modern Maturity*, September-October 2000.
- Acello, Barbara. Meeting JCAHO standards for pain control. *Nursing*, March 1, 2000.
- Acute Pain Management Guideline Panel. Acute pain management: operative or medical procedures and trauma. Rockville, MD: Agency for Healthcare Policy and Research, Public Health Service, US Department of Health and Human Services: 1992. AHCPR Publication 92-0032. (Archival only. See Agency for Healthcare Research and Quality (AHRQ.gov) for clinical practice guidelines for managing pain).
- Agarwal, R., and Enzman-Hagedorn, M. Pain and pain relief. Pp. 173-196 and 707-733 in H. L. Halliday and G. McClure, eds., *Handbook of neonatal intensive care*, 4th edition. St. Louis, Mosby, Inc., 1998.
- American Pain Society and American Academy of Pain Medicine. Consensus statement on opioid use for chronic non-malignant pain. 2001.
- American Pain Society. *Principles of analgesic use in the treatment of acute pain and cancer pain*. 4th ed., Glencoe, IL: American Pain Society, 1999.
- Anstett, Patricia. State wants people to die on own terms. Detroit Free Press, Sept. 8, 2000.
- Aronoff, Gerald M. Pain medicine: Hope is a powerful analgesic. *Geriatrics*, September 2000.
- Billings, J. Andrew. Palliative care (clinical review). *British Medical Journal*, Sept. 2, 2000.
- Bloom, BS. Risk and cost of gastrointestinal side effects associated with nonsteroidal anti-inflammatory drugs. *Arch Intern Med* 1989: 149.
- Bonn, Dorothy. Aiming for good pain care in terminal cancer. *The Lancet*, April 24, 1999.
- Borneman, Tami. caring for cancer patients at home: The effect on family caregivers, pp. 25-33 in Ondeck, Deborah Anne, and Barbara Stover Gingerich, *Home Health Care Management and Practice*. New York, Aspen Publishers, 1998.
- Brink, Susan. Soothing the littlest patients. *U.S. News*, June 12, 2000.
- Byock, Ira. *Dying Well: Peace and Possibility at the End of Life*. New York, Riverhead Press, 1997.
- Califano, Joseph A., Jr. Physician-assisted living (the Connecticut Hospice). *America*, Nov. 14, 1998.
- Cassel, Christine K. and Foley, Kathleen M. *Principles for care of patients at the end of life: an emerging consensus among the specialties of medicine*. New York, Milbank Memorial Fund, 1999.
- Cleeland, CS, et al. Pain and its treatment in outpatients with metastatic cancer. *New England Journal of Medicine*, March 3, 1994.
- Cloud, John. A kinder, gentler death. *Time*, Sept. 18, 2000.
- Colleau, Sophie M., and Joranson, David E. Fear of addiction: Confronting a barrier to cancer pain relief. In Vol. 11, No. 3, of *Cancer Pain Relief* (publication of the World Health Organization global communications program to improve cancer pain control and palliative and supportive care), 1998.
- Crawley, LaVera; Payne, Richard; Bolden, James; Payne, Terrie; Washington, Patricia; and Williams, September. Palliative and end-of-life care in the African American community. *Journal of the American Medical Association (JAMA)*, Nov. 15, 2000.
- Daaleman, Timothy P., and VandeCreek, Larry. Placing religion and spirituality in end-of-life care. *JAMA*, Nov. 15, 2000.
- Detroit Free Press. Give patients in pain a choice (editorial). Oct. 23, 2000.
- Emanuel, Ezekiel J., Fairclough, Diane L., and Emanuel, Linda L. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*, Nov. 15, 2000.
- Federation of State Medical Boards of the United States. Model guidelines for the use of controlled substances for the treatment of pain. 1998.
- Fischman, Josh. Treatments for body and mind break a cycle of agony. *U.S. News*, June 12, 2000.
- Furman, Joan. Taking a holistic approach to the dying time. *Nursing*, June 2000.
- Gabriel, SE, and Jaakkimainen, L., and Bombardier, C. Risk for serious gastrointestinal complications related to use of nonsteroidal anti-inflammatory drugs: a meta-analysis. *Ann Intern Med* 1991: 115(10).

- Girsh, Faye. Death with dignity: Choices and challenges. *USA Today* (magazine), March 2000.
- Gleckman, Howard. A dead-wrong death law. *Washington Watch*, Nov. 27, 2000.
- Goad, Meredith. Voters reject assisted suicide. *Portland Press Herald*, Nov. 8, 2000.
- Guglielmo, Wayne J. Can Doctors Put Their Fears to Rest? *Medical Economics Magazine*, Feb. 21, 2000.
- Gurland, Barry J., and Chachkes, Esther. Meeting the health care needs of the aged and disabled. Chapter 2 of *Complete Home Medical Guide*. Columbia University College of Physicians and Surgeons.
<http://cpmcnet.columbia.edu/texts/guide/toc/toc02.html>
- Hill, CS. Government regulatory influences on opioid prescribing and their impact on the treatment of pain of nonmalignant origin. *Journal of Pain and Symptom Management*, 1996: 11(5).
- Hospice Association of America. Update hospice: Core and cornerstone of the end-of-life movement. *Caring Magazine*, September 2000.
- Institute of Medicine. *Approaching death: Improving care at the end of life*. Washington, D.C., National Academy Press, 1997 (<http://www.nap.edu/readingroom/books/approaching/>).
- Jacos, A. and Dobal, M and Templin, T. Pain assessment survey. (Abstract from Presentation). 21st Annual Research Models of Health Care Conference. Midwest Nursing Research Society, April 1997. Minneapolis, MN.
- Jacox, A., and Carr, DB, and Payne R., et al. Clinical practice guidelines for the management of cancer pain number 9. Rockville, MD: Agency for Health Care Policy and Research, US Department of Health and Human Services, Public Health Service: 1994. AHCPR Publication 94-0592. (Archival only. See Agency for Healthcare Research and Quality (AHRQ.gov) for clinical practice guidelines for managing pain).
- Johnson, Dawn L. Pharmacologic Pain management for cancer patients at home. *Home Healthcare Nurse*, March 1998 (pp. 167-173).
- Joint Commission on Accreditation of Healthcare Organizations. *Hospital Accreditation Standards*. 2001.
- Joint Commission on Accreditation of Healthcare Organizations. *Pain assessment and management: An organizational approach*. 2000.
- Joint Commission on Accreditation of Healthcare Organizations. *The comprehensive accreditation manual for hospitals update 4*. November 2000.
- Joranson, D. (Personal communication) with Committee on Pain and Symptom Management. January 11, 2001.
- Joranson, DE, et al. Michigan Profile: Achieving balance in federal and state pain policy-a guide to evaluation The Pain and Policy Studies Group, University of Wisconsin Comprehensive Cancer Center. Madison, WI. 2000
- Joranson, DE, Gilson, AM and Nelson, JM. Perceived barriers to the use of Schedule II pain medications. The Pain and Policy Studies Group, University of Wisconsin Comprehensive Cancer Center, Madison. 2000.
- Joranson, DE. State intractable pain policies: Current status. *American Pain Society Bulletin*. March/April 1997.
- Joranson, DE, and Dahl, JL. Achieving balance in drug policy: The Wisconsin model. *Advances in Pain Research and Therapy*, November 1989.
- Kalb, Claudia and McCain, Cindy. Painkillers: Vicodin and Oxycontin: Hot Drugs that offer relief—and danger. *Newsweek*, April 9, 2001.
- King, Mitchell S., and Lipsky, Martin S. Evaluation of nursing home patients. *Postgraduate Medicine*, February 2000.
- Knaus, WA. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*, November 22, 1995.
- Kuebler, Kim K., and Bruera, Eduardo. Interactive collaborative consultation model in end of life care. *Journal of Pain and Symptom Management*, September 2000.
- Lagnado, Lucette. Hospice's patients beat the odds, so Medicare decides to crack down. *Wall Street Journal*, June 5, 2000.
- Larson, Dale G., and Tobin, Daniel R. End of life conversations, evolving practice and theory. *JAMA*, Sept. 27, 2000.
- Larshorne, Larry, and Stein, Wendy. Guidelines for Pain Management. *Annals of Long-Term Care*, June 1999 (special issue).

- Lawhorne, Larry. Avoidable and unavoidable decline and the naturalness of dying: The nursing home dilemma. *Annals of Long-Term Care*, August 1999.
- Lawlor, Peter G., Fainsinger, Robin L., and Bruera, Eduardo D. Delirium at the end of life. *JAMA*, Nov. 15, 2000.
- Lynn, Joanne. Learning to care for people with chronic illness facing the end of life. *JAMA*, Nov. 15, 2000.
- McCaffery, Margo. Controlling pain (cognitively impaired patients who cannot report pain). *Nursing*, July 1999.
- McCaffery, Margo. Understanding your patient's pain tolerance. *Nursing*, December 1999.
- McCarthy, Michael. Patients do not always get the best end-of-life care. *The Lancet*, June 14, 1997.
- McHugh, Paul R. Dying made easy (two men's deaths are contrasted). *Commentary*, February 1999.
- McPhee, Stephen J., Rabow, Michael W., Pantilat, Steven Z., et al. Finding our way — perspectives on care at the close of life. *JAMA*, Nov. 15, 2000.
- McQuay, Henry. Opioids in pain management. *The Lancet*, June 26, 1999. 6/26/99.
- Meier, Barry and Peterson, Melody. Use of painkiller grows quickly, along with widespread abuse. *New York Times*, March 5, 2001.
- Meisel, Alan, Snyder, Lois, and Quill, Timothy. Seven legal barriers to end-of-life care — myths, realities, and grains of truth. *JAMA*, Nov. 15, 2000.
- Merritt, Dick, Fox-Grage, Wendy, and Rothouse, Marla. *State initiatives in end-of-life care — policy guide for state legislators*. National Program Office for Community-State Partnerships to Improve End-of-Life Care, June 1998.
- Michigan Long Term Care Work Group. Report and recommendations. Michigan Department of Community Health, December 2000.
- Miller, Karl E. High-dose morphine is safe pain control at end of life. *American Family Physician*, Feb. 1, 2000.
- Mitka, Mike. Suggestions for help when the end is near. *JAMA*, Nov. 15, 2000.
- Napoli, Maryann. Grassroots movement to change end of life care. *Health Facts*, March 1999.
- Nichols, Rhonda. Managing cancer pain in managed care. *The Case Manager*, March-April 1997 (pp. 49-52).
- O'Neill, Bill. Care in the community (ABC of palliative care). *British Medical Journal*, Jan. 31, 1998.
- Oakwood Hospital and Medical Center. "My Voice — My Choice" advance directive package. May 2000.
- Pace, Brian, and Glass, Richard M. Decisions about end-of-life care. *JAMA*, Nov. 15, 2000.
- Phillips, Donald F. End of life coalitions grow to fill needs. *JAMA*, Nov. 15, 2000.
- Portenoy, RK. Management of cancer pain. *The Lancet*, May 15, 1999.
- Portenoy, RK and Payne, R. Acute and chronic pain. In *Comprehensive Textbook of Substance Abuse*. Lowinson, JH and Ruiz, P and Millman, R and Langrod, J. (Eds). Chicago: Williams and Wilkins, 1997.
- Rebagliato, Marisa; Cuttini, Marina; Broggin, Lara; et al., for the EURONIC Study Group. Neonatal end-of-life decision making, physicians' attitudes and relationship with self-reported practices in 10 European countries. *JAMA*, Nov. 15, 2000.
- Sachs, Greg A. Sometimes dying still stings. *JAMA*, Nov. 15, 2000.
- Silveira, Maria J., DiPiero, Albert, Gerrity, Martha S., and Feudtner, Chris. Patients' knowledge of options at the end of life, ignorance in the face of death. *JAMA*, Nov. 15, 2000.
- Staats, Peter S. Management of chronic pain. *The Lancet*, May 29, 1999.
- Steinhauser, Karen E., Christakis, Nicholas A., Clipp, Elizabeth C., et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, Nov. 15, 2000.
- Stephenson, Joan. Palliative and hospice care needed for children with life-threatening conditions. *JAMA*, Nov. 15, 2000.
- Substance Abuse and Mental Health Administration. Annual emergency department data. In: Data from the drug abuse warning network, Rockville, MD: Public Health Service, US Department of Health and Human Services, Office of Applied Studies. 2000
- Sweeney, Rosemarie. New Joint Commission standards focus on pain management. *American Family Physician*, Sept. 1, 1999.
- Tampa Tribune. Numbers of elderly rapidly increase, as do their many and varied problems (editorial). July 8, 2000.

- Teno, JM., and Weitzen, S. et al. Persistent pain in nursing home residents: Research letter. *JAMA*, April 25, 2001.
- Tyler, L. Evidence review on effects of unrelieved pain on the immune system. Review commissioned by American Pain Society, 2001.
- Ufema, Joy. Death and dying. *Nursing*, March 2000.
- Ufema, Joy. Insights on death and dying. *Nursing*, August 1999.
- Uniform Controlled Substances Act. U.L.A. 1990: vol. 9, part II, Sec 101.
- US Drug Enforcement Administration. Oxycontin diversion and abuse. (Information bulletin). US Department of Justice. January 2001.
- US Drug Enforcement Administration. ARCOS data for selected opioid analgesics, 1990-2000. US Department of Justice, Arlington, VA. 2000.
- US Drug Enforcement Administration, Office of Diversion Control. Diversion and abuse of prescription drugs: A closer look at state prescription monitoring programs. With National Alliance for Model State Drug Laws. April 2000.
- VonRoenn, JH, and Cleeland, CS, and Gonin, R., et al. Physicians' attitudes and practices in cancer pain management: A survey from the eastern cooperative oncology group. *Ann Intern Med* 1993: 119.
- Waters, Koko. Hospice: Comforting the dying patient. In *Gerontology Manual*, Ronald G. Stone, ed., School of Occupational Therapy and Physical Therapy, University of Puget Sound, Tacoma, Wash., 1996.
- Wennberg, John E., and Wennberg, David E. *The Dartmouth atlas of health care in Michigan*, Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Hanover, N.H., 2000.
- Whitecar, Philip S. Managing pain in the dying patient. *American Family Physician*, Feb. 1, 2000.
- Wolfe, Joanne; Klar, Neil; Grier, Holcombe; et al. Understanding of prognosis among parents of children who died of cancer, impact on treatment goals and integration of palliative care. *JAMA*, Nov. 15, 2000.
- Wooten-Green, Ron. The symbolic language of the dying metaphor and meaning. *America*, Oct. 16, 1999.
- World Health Organization. *Cancer pain relief with a guide to opioid availability* (2nd edition). Geneva, Switzerland: WHO, 1996.
- World Health Organization. *The use of essential drugs: Report of a WHO expert committee* (Technical Report series, 882). Geneva, Switzerland: WHO, 1998.
- Zerzan, Judy, Stearns, Sally, and Hanson, Laura. Access to palliative care and hospice in nursing homes. *JAMA*, Nov. 15, 2000.
- Zoloth-Dorfman, Laurie. Dying the good death — Ethical considerations at the end of life: The physician and the inevitably dying patient. *Annals of Long-Term Care*, November 1998.

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.aapm@amctec.com>
- American Pain Society:
<http://www.ampainsoc.org/>
- Americans for Better Care of the Dying:
<http://www.abcd-caring.org>
- British Medical Journal*: Pain:
<http://www.bmj.com/cgi/collection/pain>
- Center for Ethics in Health Care (for POLST form)
<http://www.ohsu.edu/ethics/polst.htm>
- Center to Improve Care of the Dying:
<http://www.medicaring.org>
- Growth House, Inc.:
<http://www.growthhouse.org>
- History of Pain Collection (University of California at Los Angeles History of Pain Project):
<http://www.library.ucla.edu/libraries/biomed/his/pain.htm>
- Innovations in End of Life Care (journal):
<http://www.edc.org/lastacts>
- Institute for Healthcare Improvement:
<http://www.ihp.org>
- Medscape Resource Center: Pain Management:
<http://neurology.medscape.com/Medscape/features/ResourceCenter/pain/public/RC-index-pain.html>
- Merck Manual of Diagnosis and Therapy — Neurologic Disorders — Pain.
<http://www.merck.com/pubs/mmanual/section14/chapter167/167a.htm>
- Michigan Hospice and Palliative Care Organization:
<http://www.mihospice.org/>
- National Hospice and Palliative Care Organization:
<http://www.nhpco.org/>
- Pain.com:
<http://www.pain.com/cme/default.cfm>
- Promoting Excellence in End of Life Care (a national program of the Robert Wood Johnson Foundation):
<http://www.promotingexcellence.org>
- Supportive Care of the Dying:
<http://www.careofdying.org>
- 10 characteristics of pain:
<http://www.medscape.com/Medscape/features/pearls/2000/03.00/cp-0302pain.html>
- Univ. of Iowa College of Nursing-International Center for the Control of Pain in Children and Adults:
<http://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.

Diversion. 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, it 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 *at 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.

Appendix A: Executive Orders.

EXECUTIVE ORDER No. 1999 – 4

June 11, 1999

*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.

EXECUTIVE ORDER No. 2000-2

January 24, 2000

*MICHIGAN COMMISSION ON END OF LIFE CARE
MICHIGAN DEPARTMENT OF COMMUNITY HEALTH
AMENDMENT TO EXECUTIVE ORDER 1999-4*

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.

Appendix B: 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, extended-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 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 questionnaire 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 questionnaire 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(B).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(B).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(B).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(B).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(B).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(B).2 illustrates coverage for hospice sites and services.

Table VIII(B).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(B).3 illustrates coverage by indemnity/TPA and MCO care for hospital reimbursement of symptom management, acute dying, and respite care.

Table VIII(B).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(B).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(B).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.

References.

1. Coding and Reimbursement Mechanism for Physician Services in Hospice and Palliative Care. *Journal of Palliative Medicine*, Vol. 3, No. 2, 2000.
2. Ibid.
3. Michigan Department of Community Health, Michigan Behavioral Risk Factor Survey, 1999.
4. Health Insurance Association of America, *Guide to Managed Care*, 1999.
5. Michigan Hospice and Palliative Care Organization, *Annual Statistics Report*, 1999.
6. National Conference of State Legislatures, Center to Improve Care for the Dying, *State Initiatives in End of Life Care*, 1998.
7. Michigan Hospice and Palliative Care Organization, *Annual Statistics Report*, 1999.
8. National Conference of State Legislatures, Center to Improve Care for the Dying, *State Initiatives in End of Life Care*, 1998.
9. U.S. General Accounting Office, *Medicare: More beneficiaries use hospice but for fewer days of care*, GAO/HEHS-00-182, September 2000.
10. Ibid.
11. Ibid.
12. Ibid.
13. National Conference of State Legislatures, Center to Improve Care for the Dying, *State Initiatives in End of Life Care*, 1998.
14. *Last Acts, Precepts of Palliative Care*, December 1997.
15. ICD-9 Code for Palliative or Terminal Care. *New England Journal of Medicine*, Vol. 335, no. 16, October 1996.

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 prioritize among the many barriers it found and focus its efforts in areas in which it believed an immediate impact is possible. The following are high-priority areas for identification and amelioration of barriers: professional education, pain management, consumer empowerment, and insurance and regulations.

Summary of barriers.

Professional education. Perceived barriers included lack of professional training and continuing education of health care professionals in rudimentary areas of diagnosing and treating patients with 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 competency and experience in 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 of informed consent, including the right to accept or reject specific modalities of care.

Pain 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 appropriate 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 pharmacologic and nonpharmacologic 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.

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 or know that pain and symptoms can be managed without forgoing all options for curative care. Physicians fail to present all options to patients, and both physicians and surrogates often lack a good understanding of patients' goals and preferences.

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 research of the cancer disease trajectory 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 refer patients to a hospice program too early in the patient's 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 palliative care and 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 on end-of-life issues, and the absence of 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.