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End of Life Infrastructure

End of life—suffering in particular—hit the spotlight in Michigan in the early 1990’s when Dr. Kevorkian was actively practicing assisted suicide in the state. Beginning with the deliberations of the Michigan Commission on Death and Dying in 1993, proceeding through the recommendations of the Michigan Commission on End of Life Care in 2001, and continuing today with the work of the Michigan Partnership to Advance End of Life Care and many other organizations, advocates in the state have worked to improve care for persons who are dying and their loved ones. As a result Michigan has a solid and expanding infrastructure to address end of life needs.

This section provides an overview of the state’s end of life infrastructure including statutes, workforce supply and training, projects and programs, and data collection and surveillance. The information about projects and programs includes hospice and palliative care services, state and community coalitions, programs for end of life decision-making, pre-hospice services, education for consumers and caregivers, and efforts to improve end of life in long term care facilities.

Statutes Related to End of Life

Since 1978, the Michigan Public Health Code has recognized patients’ right to informed choice about medical decisions and their freedom to accept, reject, or discontinue treatment (MCL 333.20201). The Michigan Dignified Death Act (MCL 333.5651 et seq.) underscores the right to informed choice for persons diagnosed with terminal illness and further ensures their option to choose palliative pain and symptom management. The Act also emphasizes the physician’s duty to inform the patient or advocate about each medical treatment alternative and the benefits, drawbacks, and risks of each one.

In 2001, the Michigan Dignified Death Act was amended to extend the patient's right to informed choice, and the physician's duty to provide it, to persons earlier in the course of decline—to those with reduced life expectancy due to advanced illness. This change acknowledges the fact that doctors often cannot predict the duration of a person's terminal decline and that informed choice about treatment options is essential well before death is imminent. The change was intended to eliminate a known roadblock to access to hospice and palliative care services.

Michigan law also ensures that:

- Patients treated in licensed health facilities or agencies have the right to adequate and appropriate pain and symptom management as a basic and essential element of medical treatment (MCL 333.20201).
- A person can execute a Do Not Resuscitate (DNR) order to refuse revival by emergency responders should heart and breathing stop (MCL 333.1051 et seq.).
- A person of sound mind can name an advocate to make health care decisions when he can no longer speak for himself (MCL 700.5506 et seq.).
- Nursing home contracts must inform applicants of the availability or lack of availability of hospice care in the facility (MCL 333.21766).
- Hospitals upon request provide information about palliative care and the availability of hospice services in the area (MCL 333.21534).

Pain Policy

Late in 2003 the Michigan Boards of Medicine and Osteopathic Medicine and Surgery adopted model pain guidelines that had been recommended by the Federation of State Medical Boards in 1998. The Michigan Guidelines for the Use of Controlled Substances for the Treatment of Pain (2003) state that patients, especially those with terminal illness, should have access to effective pain relief. In May, 2004, to ensure adequate attention to continued undertreatment of pain, the Federation adopted a revised model policy that encourages medical boards to view undertreatment of pain as a violation as serious as overtreatment (Federation of State Medical Boards of the United States, Inc., 2004). Michigan's boards have not yet adopted this strengthened policy. Both Boards require mandatory continuing education for physician license renewal. But neither Board requires credits in pain and symptom management, even though the Public Health Code since 1997 has required "an appropriate number of hours or courses in pain and symptom management" (MCL 333.16204).

Advanced Illness

Michigan law defines advanced illness to mean "a medical or surgical condition with significant functional impairment that is not reversible by curative therapies and that is anticipated to progress toward death despite attempts at curative therapies or modulation, the time course of which may or may not be determinable through reasonable medical prognostication" (2001; MCL 333.5653).



Michigan laws ensure informed choice, appropriate pain and symptom control, and other basic rights for persons with reduced life expectancy due to advanced illness.

But Michigan's pain policy does not identify undertreatment of pain as a violation of acceptable standards of practice for doctors. Although policy requires it, neither medical board has mandated continuing education in pain and symptom management for physician license renewal.

Workforce Supply and Training

Workforce Supply

The hospice and palliative care workforce is growing in expertise, with 107 physicians, 500+ nurses, and 90 nursing assistants that have earned end of life certifications. There are more than 8000 hospice volunteers.

Of the 107 physicians, 69 are board-certified in hospice and palliative medicine and 56 are certified as trainers for the EPEC™ Project; 18 hold both credentials. EPEC™ is a curriculum for Education on Palliative and End-of-life Care for physicians and other health care disciplines. In addition to the 56 physicians there are nine other health professionals certified as EPEC™ trainers.

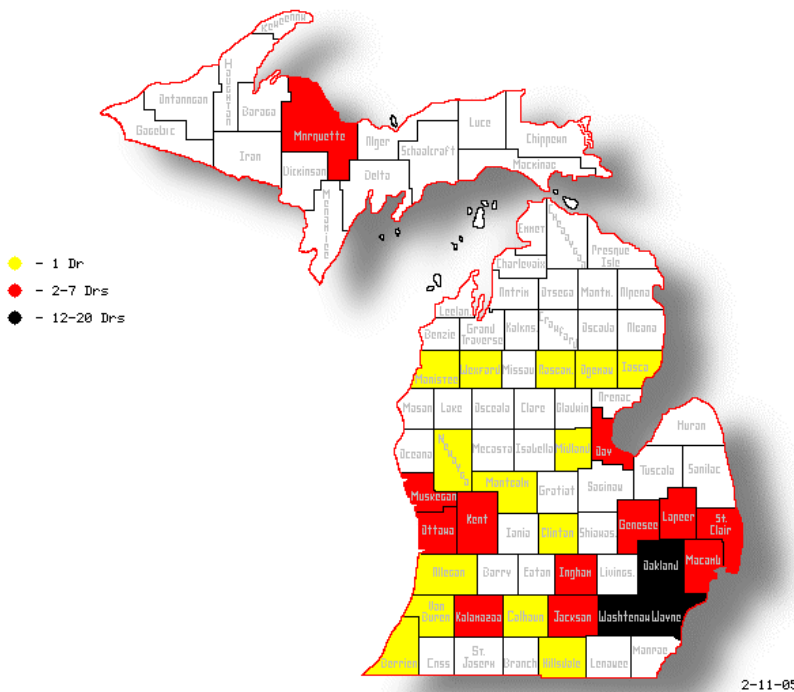
These doctors with end of life certifications work as practicing clinicians and many also serve as hospice medical directors or medical school faculty or both. Their specialties include palliative care, internal medicine, geriatrics, oncology, family practice, pediatrics, emergency medicine, and pulmonary medicine, among others. These physicians are located in 29 of Michigan’s 83 counties. See Figure 9.1 for a map of their distribution.



90% of doctors with end of life credentials work in the southern part of the state where almost 90% of deaths occur.

Overall, 1/3 of Michigan counties have one or more physicians with formal training and certification in end of life care.

Figure 9.1. Distribution of Physicians with End of Life Certifications



Of the 500+ nurses, 246 hold national certification as hospice and palliative nurses (CHPN), 5 as advanced practice nurses board-certified in palliative care management (APRN, BC-PCM), and 11 as certified hospice and palliative licensed nurses (CHPLN).

The End-of-Life Nursing Education Consortium (ELNEC) project is a national program to improve end of life care by nurses. As of February, 2005, there are 40 Michigan nurses certified as ELNEC trainers in one of four curriculums—28 baccalaureate, 4 graduate, 5 pediatric, and 3 oncology. Well over 300 nurses have been trained in several ELNEC courses in the state.

Physicians and others certified in the EPEC™ curriculum and nurses trained in the ELNEC curriculum are expected to educate others. It is likely that EPEC™ and ELNEC trainers have conducted courses for their peers in Michigan, but participation has not been fully reported or tracked.

Workforce Training

End of life education is moving forward for state professionals.

Nursing Education

Michigan's major nursing schools have faculty with end of life training and certifications and they are incorporating end of life content into their curriculums to varying degrees. Methods include presenting ELNEC modules to faculty and encouraging their use, surveying faculty to determine end of life content in existing courses, and comparing ELNEC content to course content and matching missing pieces to appropriate courses. The common approach among stakeholders interviewed has been to integrate ELNEC content into the curriculum; two also offer one credit courses, one on pain management and one on dignified dying.

Madonna University has the nation's only university-based degree program in hospice education, and the nursing school there offers a masters level specialty in palliative nursing—the first such program in the state and the fourth in the nation.

The University of Michigan Palliative Care Education Initiative focuses on education and research to improve end of life care. One project was an end of life training program for nurse champions who then coordinated quality improvement projects in clinical units across the health system. Another was a baseline end-of-life assessment during the nursing training blitz for annual institutional competencies, which led to development of palliative care content for the orientation for new nurses plus three to four nursing in-



Michigan schools of nursing have taken steps to integrate end of life content into their curriculums. Several have an ELNEC-trained faculty member.

Madonna University's College of Nursing and Health has one of the nation's four masters programs in palliative nursing and the only degree program in hospice education.

services annually on palliative care priorities. A third project has been production of two videos that show successful handling of difficult end of life situations; they are intended for use as training tools for university courses and other groups to spark discussion and promote multidisciplinary collaboration.

Since 1999 the End of Life Center of Excellence located in the College of Nursing at Michigan State University has combined research, education, and community service to advance the art of caring for persons in advanced stages of chronic disease. The ultimate goal of the Center is to develop care delivery models that will enhance quality of life for these persons and their caregivers. Among the research priorities are symptom management, decision making, and family/caregiver needs. One project studied the use of telehospice for rural areas in Michigan.

Medical Education

In 2003 the Michigan State University College of Human Medicine was runner-up for the Paul R. Wright Excellence in Medical Education Award for integrating palliative care and end of life into the medical education curriculum.

Also housed at Michigan State University is the Geriatric Education Center of Michigan (GECM), a statewide consortium that began in 1987 to advance geriatric education for physicians and other health professionals in the state. Member organizations collaborate with a number of provider, public health, and academic partners to enhance quality of and access to health care services for older adults, especially high risk groups. The GECM was centrally involved in developing nursing home guidelines for end of life care and pain management and provides training in continuous quality improvement to help facilities implement the guidelines. The GECM extends its reach to rural areas across Michigan through video teleconferencing.

Wayne State University, the John D. Dingell Veterans Administration Medical Center in Detroit, and Hospice of Michigan are collaborating for a 2005 launch of one of the nation's few medical fellowships in hospice and palliative medicine. The planned structure for the fellowship is 9 months of inpatient palliative care and 3 months of hospice home visits and administrative training.

Michigan's four colleges of medicine report considerable attention to end of life care in courses and in one case, clinical experience. They have worked to share resources and coordinate efforts in



Michigan's four colleges of medicine have taken steps to integrate end of life content into their curriculums. The MSU College of Human Medicine won national recognition for their efforts.

Most primary care residencies in Michigan hospitals provide training in pain and symptom management, but there is little or no training in end of life care in many residencies for other specialties.

curriculum and faculty development (Michigan Commission on End of Life Care, 2002).

According to stakeholders, there is considerable variation in attention to end of life education and experiences in postgraduate medical education in Michigan. Some residencies teach all or part of the EPEC curriculum, others require a day or two spent with hospice staff, and many do not address end of life issues at all.

A survey of the state's 275 residency and fellowship programs in 2000 yielded a 70 percent response rate, half from primary care programs and half from other specialties. Half of the programs offered no training in end of life care (Michigan Commission on End of Life Care, 2002). These were some of the overall findings:

- 56 percent reported coursework in pain management, 46 percent offered training in end of life care, and 31 percent required exposure to hospice.
- Primary care programs devoted the most time to end of life—84 percent required training in pain management, 76 percent in other symptom management, and 74 percent in determining prognosis.
- Lecture was twice as common (85 percent) as clinical experience (43 percent) as a training format (Ogle & Mavis, 2004).

Other Education

Wayne State University offers a successful interdisciplinary course in end of life issues. The project features ongoing collaboration of 16 academic units plus local hospice and hospital providers and will publish a book of case studies in 2005.

Michigan State University offers a course in palliative care in the graduate social work program and a bioethics boot camp for physicians and other disciplines.

Michigan professional and trade organizations offer a growing number of continuing education sessions on end of life topics, and most hospices work to educate doctors and other professionals about pain and symptom management, hospice services, and other end of life concerns.

End of life training tailored for social workers is available via a new curriculum developed by the national Social Work End-of-Life Care Education Project. One of the project leaders is a Michigan practitioner. The Michigan Hospice and Palliative Care Organization sponsored a 2-day training in 2004.

Projects, Programs, Resources

Hospice and Palliative Care Services

Hospices are the primary providers of palliative care in the state.

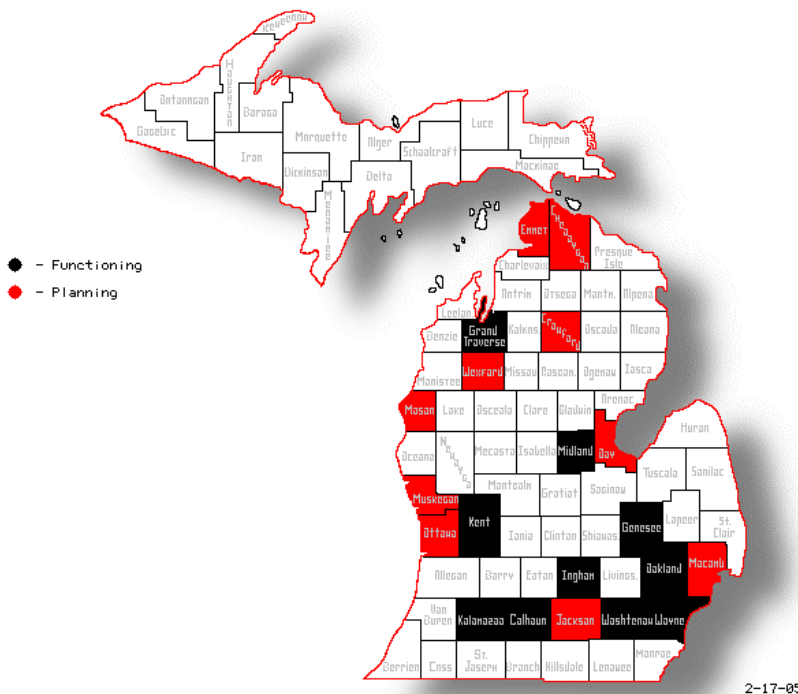
- Michigan has 146 licensed hospice agencies. Together, they serve every county. In 2002 they served an estimated 29,400 persons at the end of life.
- There are 10 licensed hospice residences in Michigan. Of their combined 164 beds, 110 are in southeastern Michigan, 31 are in Lansing, and 23 are in Kalamazoo.
- There are a number of small hospice homes in communities around the state. They are non-licensed and supported by community donations. More are in the planning and fundraising stages. There is no organized tracking of these non-licensed homes, so a complete count is not available.



Each of the 83 counties in the state is served by at least one hospice, but only 10 counties have hospitals with inpatient palliative services. Most of these facilities are located in urban areas in southern Michigan.

Seventeen health systems in metropolitan areas have launched palliative care services; 16 others are in various stages of planning. Figure 9.2 shows county locations of functioning and planned programs.

Figure 9.2. Location of Health System Palliative Care Services by County



Ingham, Oakland, Washtenaw, and Wayne counties have functioning palliative care services at multiple hospitals, and Genesee and Kalamazoo counties each have one additional program in the planning stages. There are two community-based palliative care programs—in Midland and in Traverse City—that offer both inpatient and in-home consultations. Both programs are housed in home care agencies that are affiliated with a health system and have a licensed hospice program.

Functioning palliative care programs are concentrated as the population is, in the southern half of the Lower Peninsula. Many of the planned programs are in rural counties. Other areas of the state have access to palliative care only through hospice providers, EPEC-trained physicians, and pre-hospice programs in some home care agencies.

- Hospital-based palliative care programs are not licensed separately from the sponsoring organization, so there is not yet any organized tracking of where they are located or what services they provide.

One southeastern Michigan visiting physician group led by a geriatric specialist has linked with a local hospice for palliative care continuing education. The group is one of 12 that participate in a national best practices consortium through the American Academy of Home Care Physicians.

End of Life Research

Academics and clinicians at Michigan's major universities and clinical centers conduct a variety of research projects related to end of life care. Some of them involve collaboration with other scholars, health care systems, and hospice providers.

One example is a joint Phase III clinical trial conducted by the University of Michigan Comprehensive Cancer Center and Hospice of Michigan. The study tested the impact of providing comprehensive palliative care for persons who were still receiving anti-cancer treatment. Preliminary results were promising.

Hospice of Michigan is home to the only privately endowed end of life research center in Michigan. The Maggie Allesee Center for Quality of Life conducts research, education and community outreach initiatives aimed at improving care for persons who are seriously ill and their caregivers. The Center has collaborated with a variety of university and health system partners for projects that have received funding from national organizations.

State Coalitions

There are six statewide coalitions related to end of life in Michigan. They target a variety of priorities including cancer and cancer pain, dementia, pediatric palliative services, outreach to ethnic groups underserved by hospice, end of life in nursing homes, and hospice services for veterans. They operate with a range of organizational structures, budgets, and staffing, but all have successfully achieved a number of key objectives.

Michigan Cancer Consortium

This group has been evolving for two decades but has been a consortium of organizations since 1997. The Consortium has funding from the Centers for Disease Control as well as a state appropriation for cancer control and is considered by the CDC to be a gold standard for state cancer consortiums. It is well-staffed and has a sophisticated structure and processes for assuring active member participation and for tracking results. Currently there are 78 member organizations working to achieve 10 objectives, one of which is to increase the timeliness of referrals for end of life care for persons with breast, cervical, colorectal, lung, or prostate cancer.

Michigan Cancer Pain Initiative

The MCPI is part of a network of state and international pain initiatives endorsed by the National Institutes of Health and other organizations. Goals include educating health professionals and consumers and eliminating barriers to cancer pain relief. During 2001, Michigan was one of five states to participate in a successful quality improvement project to institutionalize effective pain management practices. The MCPI has modest funding through early 2006, but the group has been inactive since late 2003. Without staffing it became difficult to find members to assume leadership roles.

Michigan Partnership for the Advancement of End of Life Care

The Partnership began in 2000 with a three-year grant from the Robert Wood Johnson Foundation and a focus on educating health professionals, improving end of life care in nursing facilities, and developing resources for outreach to diverse populations. The Michigan Hospice and Palliative Care Organization (MHPCO) has served as the managing entity for the Partnership since it began and continues to do so. Since the RWJ funding expired, the Partnership has maintained strategic projects and continuing education through smaller grants from the Michigan Department of Community Health and other sources. Achievements include a web-based end of life resource center, several ELNEC trainings



Six statewide coalitions focus at least in part on improving end of life care. Ten community coalitions do the same. Each has achieved success with its own objectives.

With limited time and resources, it is difficult to network and to coordinate efforts to generate the power of collaboration for cross-cutting goals.

and annual conferences, hospice/nursing home training and toolkit, pediatric palliative care and veterans hospice work groups, and a toolkit for community end-of-life outreach. MHPCO also has built a broad organizational membership for the Partnership.

Michigan Dementia Coalition

This group has been evolving for the past two decades. It is a statewide collaboration of consumers, community groups, universities, and state agencies. Their common aim is to improve the quality of life for persons with dementia and their families. Coalition goals address caregiver support, dementia diagnosis and management, and education of health professionals, policymakers, and the public. The coalition established a Hospice and Palliative Care Work Group in 2002. The group has been working to educate consumers and professionals about hospice for persons with late stage disease. The Michigan Dementia Coalition receives staff support through the Michigan Public Health Institute.

Michigan Alliance for Pediatric Palliative Services (MAPPS)

This coalition of more than 40 individuals, hospitals, hospices, and insurers has been meeting since 2003 for the purpose of improving palliative care for children with serious illness. The three-pronged focus is community awareness, professional education, and policy improvements. The group surveyed physicians and hospitals to assess pediatric palliative services and is developing a strategic plan. The MAPPS survey was funded by a Rallying Points grant. MHPCO has provided unpaid staff support.

Hospice Veterans Partnership

These partnerships were mandated by the Veterans Administration; this group began meeting late in 2003. Members represent hospices and each VA health care facility in the state. Goals are to strengthen relationships between hospice providers and veterans organizations, to promote shared understanding of each others' mandates and services, and to facilitate continuity of care and a single point of access to hospice care for veterans. Initial activities have focused on assessing partners' needs and exchanging education. The CEO of MHPCO helped to launch this group. There is no paid staff support.

Community Coalitions

There are ten active community coalitions in Michigan, most located in the southern half of the Lower Peninsula. Five focus on educating citizens about advance care planning; those in Traverse City, Muskegon, and Mid-Michigan have used Rallying Points grants to offer training in the Respecting Choices process and tools

so their members can help people develop advance directives. A coalition in the Lansing area focuses on hospice outreach to underserved ethnic populations. One in Keweenaw promotes community grief support. While not a formal coalition, a Jackson community work group has focused upon developing a form and procedures to honor people's end-life treatment preferences in health care and community settings. The Flint coalition is working on end of life education for nurses, and the Grand Rapids coalition has sponsored a variety of activities including a conference on caregiving at end of life.

Traverse City, Kalamazoo, Frankenmuth, and Muskegon have used or adapted the community survey tool developed by the Missoula Demonstration Project to conduct comprehensive assessments of residents' end of life knowledge, attitudes, expectations, and experiences. Response rates have been solid, and the data has been useful to plan initiatives and build stakeholder support for them.

Programs for End of life Decision-Making

Along with community coalition activities to promote advance care planning, there are successful programs that focus on improving end of life decision-making in a variety of health care settings.

The Advance Care Planning Department at Munson Medical Center in Traverse City is a model of community engagement. Along with a well-established Respecting Choices program, there are now efforts underway to improve end of life decision-making in nursing homes, in critical care units, with legal guardians, with heart failure patients, and with community mental health clients.

The Family Matters Support Service at Oakwood Healthcare System in Dearborn is a team of registered nurses who help patients and their families with end of life goals and treatment decisions in the inpatient setting. They have developed an advance directive tool and planning process that can be licensed for use by other organizations.

Hospices in Lansing, Jackson, and Holland dedicate staff time to in-home information visits to help prospective patients and their families consider goals and treatment options and make informed choices about end of life care.

Pre-Hospice Services

Of the 57 hospice contacts interviewed, 29 work in home-health-based hospice programs. Almost all of those agencies (90%) offer special services for home care patients who have end of life needs



A number of Michigan health care providers have developed promising programs for end of life decision-making and symptom management. These innovations could be adopted in other settings.

but are not yet eligible or emotionally ready for hospice. The services include hospice-like pain and symptom management and emotional support. The care team generally includes nurses, social workers, and home health aides and occasionally other disciplines. Most often the staff members are trained in both home health and hospice so that continuity of care and caregivers is ensured if the patient transitions to hospice.

A number of hospices and health systems have developed innovative strategies for meeting needs of people who do not yet qualify for hospice care but have the same intensity of need for support. Services are free of charge. Examples include:

- Temporary services (mainly home health aide) to bridge the gap between home care and hospice, provided by the health system's private duty home care agency and funded by the hospital foundation;
- Social work and nursing evaluation and support as needed for cancer patients who are not homebound and still are receiving active treatment; funded by the hospital foundation; and
- Chores and transportation provided by hospice volunteers for chronically ill and debilitated persons who do not yet qualify for hospice; expenses are covered by hospice fundraising.

Consumer Education and Caregiver Support

Almost all hospices devote much time and effort to informing consumers about hospice care.

- The most common method is presentations for community groups to raise awareness and dispel misconceptions about hospice services.
- At one agency, specially selected and trained bereaved family members provide peer consults for families who are considering hospice services.

Caregiver Support

Caregiver support is part of hospice care, provided by the interdisciplinary team as well as by volunteers. Three of the interviewed hospice contacts reported special programs for caregiver respite and support.



Hospices provide caregiver mentoring and support, and respite care and other support services are available through Area Agencies on Aging. In most areas, the need for support exceeds the supply of services.

- Brief respite care provided by volunteers is a standard service for all hospices, but at one hospice some volunteers stay overnight to allow the caregiver a restful sleep.
- Another hospice provides 16 hours of free respite care per week for each hospice family. The service is provided by private duty home health aides and funded by donations. More than half of the families use at least some of the hours each week.
- How-to training for caregivers is uncommon, but one hospice has trained a squad of mentor volunteers who make home visits to help caregivers learn skills like mouth care, bathing, and how to turn and comfortably position their loved ones.



Hospices provide grief assessment and bereavement services. Funeral homes and other community agencies also may provide grief support groups. There is no central source of information.

The American Red Cross has developed a nine-module family caregiving course that can be offered as a series of classes or for home study. The program is offered by the Washtenaw County Chapter and may be available elsewhere.

Respite care and other support services are available through Area Agencies on Aging, with funding from the National Family Caregiver Support Program via the MDCH Office of Services to the Aging. Hospice contacts report that need exceeds supply. The Michigan Dementia Coalition has established a work group with the Office of Services to the Aging to strengthen respite services for dementia caregivers.

Area Agencies on Aging, hospitals, and hospices have offered support groups for caregivers but encounter low participation even with in-home respite and transportation. Some have had success with informal get-togethers at restaurants, and one Area Agency offers a caregiver support line that is answered by a social worker.

Some disease-focused nonprofits offer support groups for patients or caregivers or both. For instance, the Alzheimer's Association has a wide network of groups throughout Michigan, and the Michigan Parkinson Foundation sponsors 49 support groups across the state. These groups address end of life issues as they arise.

Grief Support

Medicare regulations mandate that hospices provide bereavement services to family survivors for 13 months after the patient dies. The scope of services varies with the hospice but may include initial assessment (by phone or in person as needed) followed by

periodic phone or mail contact or both to give families the option of further support if desired.

- Most hospices offer grief support groups; those with enough resources tailor them to meet loss-specific needs—for example, groups for younger spouses, for bereaved parents, or for suicide survivors. Many organize memorial services periodically to meet with families and honor those who died.
- Individual counseling may be offered for persons experiencing complicated grief. A few hospices offer grief centers and summer camps for bereaved children.

Bereavement services also are available through funeral homes in some communities. Eight organizations in Michigan offer grief support using resources developed by the American Association for Retired Persons. The AARP offers materials and instructions for one-to-one outreach for the newly bereaved and a six-session educational series, as well as a leader's guide for support groups.

Madonna University's Hospice Education Program has a grant to establish a collaborative community grief center to provide counseling and support for bereaved individuals as well as education for the community and training for professionals.

Grief support is a new idea for hospitals. There are examples in Michigan neonatal intensive care units of caring rituals that staff members provide to help families cope with a baby's death. Chaplains and unit staff in some facilities send sympathy cards to families of patients who died there.

One of the more comprehensive palliative care programs in the state formed a bereavement task force to oversee grief support services for dying inpatients and their families. In-house elements include private rooms and comfort carts to help families create a peaceful space and specially trained volunteers to be present as needed so no one dies alone. The team sends sympathy cards and twice a year conducts memorial services, and 6 to 8 weeks after each death a pastoral care volunteer telephones the family to offer condolences and help finding community support if desired.

Improving End of Life in Long Term Care Facilities

Most hospices offer training and continuing education for nursing home staff and repeat it often to help the facilities cope with staff

changes due to turnover. Some have developed innovative approaches to training. Two examples are:

- Providing hospice volunteer training for nursing home staff, completing the program in 12 monthly chunks; and
- Training exemplary hospice nursing assistants to deliver end of life training sessions for their peers in long term care facilities.

An innovative service developed by a former nursing home nurse and provided by one hospice matches specially trained hospice volunteers with dying nursing home residents to provide a continuous presence at the bedside. Along with providing person-centered comfort, this practice ensures that no resident dies alone and allows facility staff to continue their other duties.

Hospice in Nursing Homes

Hospices that report the greatest success serving nursing homes (more patients, more collaborative relationships) have assigned consistent staff to the facilities. These are some benefits:

- As the nursing home and hospice team members get to know one another, they learn to understand each other's procedures and regulations. Relationships build, trust grows, and patient care improves.
- Nursing home nurses begin to ask about other individuals and eventually begin to refer more residents for hospice care. They also begin to apply palliative care principles for non-hospice residents.

Quality Improvement

Several consultation and quality improvement programs target end of life issues in nursing homes. These include the following:

- MDCH Bureau of Health Systems Quality Improvement Nurse Consultants;
- Michigan Public Health Institute (MPHI) Center for Long Term Care; and
- Nursing Home Quality Improvement Initiative implemented in this state by the Michigan Peer Review Organization (MPRO).



Hospices that report the greatest success serving nursing home residents have assigned consistent staff to the facilities. Both teams learn from repeated contacts, and patient care improves.

A number of quality improvement initiatives in nursing homes have achieved modest reductions in prevalence of serious daily pain.

Results of these programs include:

- Free training and consultation for nursing homes about quality matters including end of life care and pain and symptom management.
- Clinical Process Guidelines for end of life care and for pain management. Nursing homes can use these to assess their systems and processes and guide improvement. State surveyors use them to evaluate a nursing home's performance and needs for improvement.
- A two-year quality improvement project to help nursing homes improve pain assessment and treatment for short stay (acute) and long term (chronic) patients.
 - After one year the prevalence of chronic patients with daily pain at moderate to excruciating levels dropped from 13% to 6%.
 - The prevalence of patients with moderate to excruciating pain in the acute group fell from 30% to 23%.

In 2003 the Michigan Hospice and Palliative Care Organization and the Michigan Association of Homes and Services for the Aged collaborated on a joint training for nursing home and hospice professionals. Their aim was to facilitate collaboration for end of life care. They developed a toolkit with a CD ROM, educational resources and videos from the training; it is available for purchase through MHPCO. Hospices can use the materials to aid collaboration with nursing home partners.

Data Collection and Surveillance

Michigan Death Certificate

Michigan has a gold standard cancer registry, and mortality data from death certificates are available from the Vital Records and Health Data Development Section at the Michigan Department of Community Health.

- Through 2003 there was a field on the death certificate to indicate where the death occurred and another to specify where death was pronounced.
- Of the two indicators, place of death is most useful for determining where the person received care at the end of

life. Since it is not uncommon for persons who die elsewhere to be transported to a hospital and pronounced dead there, the where- pronounced indicator artificially inflates the frequency of hospital deaths.

- When the Michigan form was revised—effective January 1, 2004—the field for place of death was removed.
- The place-of-death field provided useful data, not otherwise available, about where people received care at the end of life.

The national standard death certificate includes an optional item that indicates whether or not the decedent received hospice care, but Michigan has not added that field. Changing fields on the death certificate is a complex task because it requires agreement from a broad group of users. It is likely to be several years before the current form is reviewed and potential changes are considered.

A number of mortality reports are accessible and updated annually on the Michigan Department of Community Health website.

- They provide death counts and rates by age, gender, race, and cause. The data are presented for Michigan; some reports also are available by county.
- Data can be specially requested from the MDCH Vital Records and Health Data Development Section if a desired report is not available online.

Behavioral Risk Factor Surveillance Survey

Michigan has developed a special cancer Behavioral Risk Factor Surveillance Survey (BRFSS) with an end of life module included. The end of life questions assess respondents' knowledge of and experiences with issues related to end of life. Questions for caregivers address place of death and various aspects of pain and symptom management.

The survey is designed to over sample persons from diverse cultures so that final results represent the state's entire population. The Michigan Public Health Institute coordinates the special cancer BRFSS with funding from the Michigan Department of Community Health. The first survey was conducted in 2001/2002, and it was repeated in 2004. The data is useful for program planning and funding requests. It is available to interested users by request.



Data about death in Michigan are collected in varied forms:

- Death certificates
- BRFSS consumer survey
- Health care provider assessments and claims.

There is no organized system for compiling the data to monitor end of life issues.

When the Michigan death certificate was revised for 2004, the field for place of death was removed.

- This field provided useful data, not otherwise available, about where people received care at the end of life.
- It is likely to be several years before the form is next updated.

Other Sources of Data

Health care providers that treat persons at the end of life collect data that are useful for tracking end of life needs and outcomes

- This is true for hospitals, nursing homes, home care agencies, hospice programs, palliative care programs, community mental health agencies, and other community and long term care service providers.
- Examples of data include client demographics, referral source, diagnosis, pain level, presence of advance directives and end of life preferences, admission and discharge dates for length of service, and reason for discharge.
- In mandatory periodic assessments of all clients, home health agencies and nursing homes indicate whether the person has end-stage disease (6-month prognosis).

Although such data is collected, for some providers—hospices and palliative care programs, for instance—there is no required reporting. Hospitals, home health agencies, and nursing homes transmit their data to distinct repositories. There is no organized system for compiling data elements from all of these sources to monitor end of life issues.

Implications for Policy and Programs

This overview of Michigan's end of life infrastructure raises several implications for future efforts.

Implement Existing Policies

Michigan's pain policy is an example of what can happen when advocacy efforts do not include a plan to ensure that policy changes are implemented as intended by policymakers. Striking a balance between pain management and drug control is difficult—the issues are complex and politically sensitive and the involved units hail from different departments in state government. Yet undertreated pain is a serious public health problem nationwide and in Michigan.

The MDCH bears responsibility for protecting the public's health and assuring access to appropriate health care. The units responsible for drug control policy, for licensure of health



Chinks in Michigan's end of life infrastructure include medical practice that does not match policies, uneven access to services, lack of consumer education, and lack of surveillance of end of life data for the population.

Solutions lie within the state's rich supply of end of life talent and programs. A neutral convener could help stakeholders:

- Network to exchange innovations.
- Collaborate to tackle shared needs.
- Leverage scarce resources.

professionals, and for the Michigan Automated Prescription Program are housed within the Department. To align practice with policy, two steps are recommended:

- Seek internal understanding and accord about pain policy and practice.
- Approach units from other departments (Attorney General, law enforcement) to solicit their active support.

Future advocacy efforts should include a plan for action when new policy is adopted. This approach would increase the odds that needed communication, education, and process changes occur.

Ensure Access to Services

Beyond hospice providers, palliative care expertise seems to be rare in most Michigan counties. It would be reasonable for the MDCH to foster regional collaboration to improve access to palliative care for persons with advanced illness. Elements of a solution might include the following steps:

Identify local providers with palliative care expertise;
Adapt consultation or pre-hospice models that work elsewhere; and
Offer EPEC and ELNEC trainings locally.

Policy options might be to require hospitals that participate with Medicaid to do the following:

- Retain at least one physician on staff with palliative care certification;
- Conduct annual in-service training on pain and symptom management for all employees; and
- Report annually certain quality indicators related to pain management at the end of life.

Coordinate Collaboration

With 17 palliative care programs, 10 community coalitions, and 6 statewide coalitions, it would be fruitful for these groups to connect and collaborate. This would enable them to leverage scarce resources, learn from each other, and work together on cross-cutting issues.

"We have the right environment for superior end of life programs, but we haven't sustained efforts or reminded citizens and organizations that the issue is important. Same as with immunization, action dwindles without alerts."

Spread Innovations

Providers in diverse health care settings have devised innovative strategies for dealing with end of life care and education. Many of the ideas could be implemented readily by other agencies to meet similar needs across the state. A neutral convener is needed to enable networking and exchange of innovations. To support action it may be useful to provide templates, toolkits, or trainings for targeted interventions.

Educate Consumers

Input from hospice contacts and stakeholders affirms the conclusion of the Michigan Commission on End of Life Care:

- People are not aware of their rights to informed choice and effective pain and symptom control and they suffer because of it.

There never has been a sustained, comprehensive public awareness campaign about these issues in the state, and there needs to be.

Launch a Surveillance System

Compelling data helps to build urgency for change. A neutral convener needs to facilitate a process to identify data elements from each care setting and from existing data sources, select indicators to monitor, and set up an organized system to access, monitor, and share the data.

Key Points

Michigan laws ensure informed choice, pain and symptom control, and other rights for persons at the end of life. Many people are not aware of their rights and suffer because of it. There needs to be a comprehensive, sustained public awareness campaign.

Although policy requires it, professional boards have not mandated continuing education in pain and symptom management for license renewal.

Access to doctors and hospitals with palliative care expertise is uneven statewide. Action is needed to ensure equity of access in underserved regions.

Michigan schools of nursing and medicine have taken steps to integrate end of life content into their curriculums. While most primary care residencies provide training in end of life care and pain control, many residencies for other specialties do not.

Several statewide and community coalitions focus at least in part on improving end of life care. With limited resources it is important but difficult for them to collaborate to achieve shared goals.

Michigan providers have developed promising programs for end of life decision-making, symptom management, and consumer and caregiver education and support. These innovations could be adopted in other settings if there were a forum for networking and exchanging ideas.

Persons at the end of life and their caregivers need respite care and other types of support. In most areas, the need for support exceeds the supply of services.

Hospices and other community agencies provide grief support services. There is no central source of information or coordination of services.

A number of quality improvement initiatives in nursing homes have achieved modest reductions in prevalence of serious daily pain. Hospices that report the greatest success working with nursing homes assign consistent staff to the facilities.

There is a wealth of data about end of life from a variety of sources in the state but no organized system for compiling it to monitor needs and progress.

Michigan has a rich supply of professional talent and promising programs. A neutral convener could help them collaborate to tackle shared needs.