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Key Points

Strengths, Obstacles, Lessons Learned

Michigan's considerable end of life infrastructure and services are the result of years of persistent effort by a legion of committed and resourceful individuals and organizations. For the most part these advocates have risen above competition and narrow allegiance to embrace collaborative alliances for the greater good. They have built a solid statutory base to protect citizens' rights to informed choice and palliative care during life-limiting illness. They have designed model academic curriculums and professional training seminars to prepare the workforce to deliver quality end of life care. They have created innovative models of service delivery to link people and their caregivers with the end of life treatment and support that they need.

Most of the interviewed stakeholders and hospice contacts have been active participants in these efforts to advance end of life care. This section summarizes their input about the strengths of their work and the obstacles to progress related to these key themes: policy and advocacy, collaboration and leadership, system and resource issues, and provider and consumer concerns. The section concludes with a discussion of lessons learned and implications for policy and programs.

Policy and Advocacy

Strengths

Successful advocacy efforts over the past two decades have resulted in laws that protect individuals' rights related to end of life decision-making and treatment. Political support for end of life issues seems to be growing.

Policy & Advocacy

Strengths
End of life statutes
Advocacy skills
Receptive policymakers

Obstacles
Policy without action
Persistent policy barriers
Political roadblocks

End of Life Statutes

Michigan laws related to end of life issues have evolved and expanded since the 1978 Michigan Public Health Code recognized patients' rights to informed choice about medical decisions. Now there are statutes that protect an individual's right to choose palliative care (including hospice) as a treatment option, to designate a patient advocate to make medical decisions when she cannot, and to defer resuscitation when heart and breathing stop. There also are laws that protect a person's right to effective pain management as a basic element of treatment, laws that protect physicians who prescribe controlled substances when medically appropriate, and laws that mandate continuing education in pain management for physicians and other health professionals.

Michigan laws protect individuals' rights related to end of life decision-making and treatment. Many legislators support long term care and end of life issues; in most cases end of life legislation has attracted bipartisan support.

Advocacy Skills

Advocates have been successful at educating policymakers about end of life issues and about the steps required to remove policy roadblocks to basic patient rights and treatment. Many of the recommendations have come from appointed commissions and from hospice professionals. The Michigan Hospice and Palliative Care Organization has spearheaded some advocacy efforts and collaborated on others.

Stakeholders who have been involved in these efforts listed strategies that contribute to success:

- Involving all affected constituents;
- Making a plan and persistently going after it;
- Writing proposed language for the bills and dividing them among several legislators to sponsor; and
- Asking what information is needed to pass the bills and providing the suggested input in the requested format.

When stakeholders followed this approach, they were told that no one had ever testified the way they did.

Receptive Policymakers

Many legislators support long term care and end of life issues. Some are health care professionals. Some have worked in the long term care industry. Others have had personal or family experiences with life-threatening illness or end of life situations. These lawmakers have a record of responding to policy requests and getting them passed. In most cases end of life legislation has attracted bipartisan support.

Ensuring quality end of life care also fits the governor's values. She has committed to serving the vulnerable and has worked to protect Medicaid during difficult budget negotiations. Her

administration is open to doing things differently. While there is no end of life presence in *Healthy Michigan 2010*, it may be that the governor and surgeon general are not yet informed about end of life issues and would be supportive if they were apprised.

> *"Dr. Kevorkian's activities were politically motivating. If people resort to a rusty van in the middle of the night, something must be very wrong with end of life care. His actions raised awareness of the need for choice. And then the resounding defeat of the physician assisted suicide referendum in 1998 generated commitment to offer better alternatives."*

Policy and Advocacy Obstacles

Stakeholders' 32 mentions of policy obstacles outnumbered policy strengths by a ratio of 3:1. Most frustration revolved around three themes: policy without action (13 mentions), remaining policy barriers (11), and political roadblocks (8).

Policy without Action

Establishing policy and passing laws only to have practice remain the same was a common frustration for stakeholders. They offered several reasons why this happens:

- Many organizations are strong at advocacy but weak at rolling out action to implement the change. Advocates feel a sense of mission accomplished once bills are passed and move on to the next issue.
- There is little communication to affected constituents to publicize new laws, and there is little attention to action plans for next steps.
- There is resistance to the change among those charged with implementing it and no monitoring to ensure that they take effective and sustained action—or any action at all.

Stakeholders described examples of this problem as it applies to end of life policy efforts:

- Most of the recommendations of the Michigan Commission on End of Life Care designated the Michigan Departments of Community Health or Consumer and Industry Services as responsible units. Because the directors of both departments served on the group, it was assumed that action would be taken. There were no specific plans discussed. Many of the Commission's recommendations have not been implemented.
- The third pain and symptom management advisory committee since 1994 has been dissolved and not reinstated. Many recommendations of all three groups have not been implemented.
- Professional licensing boards have not enforced the statutory mandate for continuing education on pain issues.
- State regulators in the Office of the Attorney General are not fully informed about statutory changes in pain policy.
- There has been no effective, sustained campaign to educate the public about their rights to informed choice and

effective pain and symptom management. Such a campaign was recommended by gubernatorial commissions in 1996 and in 2002.

Passing laws has not changed practice related to informed decision making and pain management at the end of life. Many were unaware of the changes, others resisted implementing them, and there was no action plan to ensure that changes would occur and persist.

Persistent Policy Barriers

Stakeholders described key policy barriers that still block effective end of life care.

Pain Policy—The Michigan Public Health Code states that "the use of controlled substances is appropriate in the medical treatment of certain forms of pain" and that "efforts to control diversion or improper administration of controlled substances should not interfere with the legitimate, medically recognized use of those controlled substances to relieve pain and suffering" (MCL 333.16204c).

However state drug policy and practices appear to be driven by a conviction that making strong opioids more available will increase drug diversion and related crime. (Opioids are used to relieve severe pain of cancer and other conditions.) Stakeholders perceive a greater focus on scrutiny of prescribing practices than on public and professional education for proper use of the drugs to relieve suffering.

Guardianship—The role of public guardians in end of life decision-making is unclear. The current Michigan bench interprets the law to prohibit guardians from deciding to withhold or withdraw treatment, regardless of the ward's medical condition or apparent best interest. This confusion has caused unnecessary suffering for some of the most vulnerable dying persons, including the persistently mentally ill and others who are not able to decide for themselves.

Nursing Home Dilemma—Federal reimbursement rules force families to choose between hospice services and Medicare payment of room and board for their dying elderly relatives in nursing homes. Most often the families choose room and board, and the patient goes without the palliative care that hospice provides.

Hospice Residence Reimbursement—Medicaid does not reimburse room and board in hospice residences, even though the rates are lower than those charged by nursing homes. Several hospice contacts identified a need for options for people who can no longer live at home (too ill, elderly caregiver, no 24-hour caregiver, etc.) but want palliative care in a homelike setting. Hospices in several

communities around the state are raising funds to construct or remodel small facilities. Donations cover the costs of room and board for patients who cannot afford to pay.

Six-Month Rule—The Medicare rule that dying persons must have a six-months-or-less prognosis to qualify for hospice care still serves as a significant roadblock to access. Medicaid follows the same rule. Physicians' reluctance to certify a six-month life expectancy until very late in the illness causes persons who are dying and their families to miss out on hospice support or to receive it for only a short time before death occurs.

The Michigan Public Health Code says that people have a right to adequate pain relief and that efforts to limit diversion of controlled substances should not hinder legitimate medical use of those drugs to control pain. But state policy and practices have focused more on scrutiny of prescribing habits than on public and professional education for proper use of strong pain medicines to relieve suffering at the end of life.

Political Roadblocks

In some instances political priorities conflict with efforts to advance end of life care. There was concern about well-meaning special interest groups and caution about the impact of administration changes and term limits.

Special Interest Groups—For every end of life gain, there has been at least one opposing faction. Right to Life of Michigan wields considerable political clout in the state, and Right to Life advocates have played a role in many end of life forums. They have not supported or opposed many of the proposed actions intended to help people express their personal wishes. Another powerful group is the nursing home lobby, whose constituents are concerned about potential loss of revenue if residents choose other settings for end of life care.

Political Turnover—A change in gubernatorial administration can disrupt implementation of policies from the previous governor's term. One member of the Michigan Commission on End of Life Care pointed out that the change in leadership following the 2002 election may be one reason why the Commission's suggestions were not fully implemented. Also, with term limits there is frequent turnover in legislators and their staff members. This underscores the need for ongoing contacts to educate them about issues of concern. One lobbyist advised thinking of a legislator as a mountain you're climbing—stay in touch and never let go.

Collaboration & Leadership

Strengths
Benefits of collaboration
Neutral leadership

Obstacles
Competition
Sustaining participation
Leadership challenges

Collaboration and Leadership

Strengths

Stakeholders from all disciplines spoke of collaboration and leadership. They saw collaboration as a strength of Michigan's end of life efforts to date. Most of the 17 mentions centered on the

benefits of working together, but people also commented about the value of having a neutral convener to lead the process.

Involving all stakeholders from the beginning of a collaboration helps to resolve conflicts, reduce turf-guarding, and improve action.

Benefits of Collaboration
Half of those who commented about collaboration cited the value of involving professionals from multiple disciplines and organizations from the beginning. This promotes airing and resolution of issues and conflicts, minimizes turf-guarding, and improves implementation of action plans.

When people from different settings work together to address a common concern, there are many advantages.

- They gain shared insight about each realm's regulatory mandates, scope of practice, expertise, and needs.
- People build relationships and trust, which generates informal consults and cooperation to benefit clients.
- Referral, coordination, and follow up are easier because familiarity builds confidence in each other's competence.
- They exchange ideas, energize each other, and reap efficiencies from not reinventing the wheel.
- People leverage scarce resources by coordinating efforts so they are complementary rather than duplicate.
- They build informal networks and through those linkages partner beyond the focus of the original project.
- Together people tackle system issues too big for any one person or organization to handle alone.

Neutral Leadership
MHPCO—The state's most visible organizational leader for collaboration on end of life issues has been the Michigan Hospice and Palliative Care Organization. Although it is an organization primarily of hospice agencies and end of life professionals, MHPCO has held a broad enough vision—to make a difference in the quality of end of life care—to serve as an administrative home for projects beyond a narrow hospice focus. MHPCO's work as managing entity for the Michigan Partnership for the Advancement of End of Life Care has been mission-driven rather than self-serving.

Michigan Cancer Consortium—The Michigan Cancer Consortium also serves as a neutral leader of collaboration among a large number of diverse organizational members. Unlike the Partnership, the MCC is staffed by public health professionals in the Cancer Prevention and Control Section at the Michigan Department of Community Health. The consortium has funding from the Centers for Disease Control as well as a state appropriation for cancer

control. The staff members are able to see opportunities for member organizations to work together and approach them to raise the possibility of collaboration.

Collaboration and Leadership Obstacles

Among stakeholders and hospice contacts, there were 29 mentions of obstacles related to collaboration and leadership. Almost half (13) centered on the issue of competition among potential partners. Others cited sustaining participation (9) and leadership challenges (7) as concerns.

Competition

Turf-guarding is an issue among end of life care providers and advocates, more among organizations and programs than among individual professionals. These are some of the examples cited:

- There is competition for patients between small and large hospices, between for-profit and not-for-profit hospices, and among hospices, home care, and nursing homes. This is compounded by a mutual lack of understanding of similarities and differences in roles and regulations.
- There is a lack of networking among hospice providers and among palliative care programs. They all deal with the same issues but seldom touch base.
- Some hospices view palliative care services as competitors and fear that they will displace hospice; they cite late or no referrals from palliative care programs as cause for concern. Others see palliative care as a complementary service.
- Collaborative practice requires continuous improvement among the disciplines involved in end of life care. Not all physicians value nurses as colleagues, and some see advance practice nurses as competitors. When clinicians from one nurse-managed health center sought to collaborate with a local hospice residence, they were declined. It was the nurses' view that the hospice medical directors considered them to be competitors.
- Major clinical centers that compete for funding, talent, and patients find it difficult to collaborate fully.
- Universities compete for funding, and university tenure systems reward independent contributions and discourage interdisciplinary work. There are turf issues within and among universities, along with lack of awareness of what others are doing. This limits coordination and collaboration.

Collaboration is a great strength of end of life projects in Michigan. It offers many benefits: leveraging scarce resources, partnering to serve clients, and tackling issues that no agency can handle alone.

Collaboration can be difficult to maintain due to competition and turf-guarding, lack of time and other resources, and varying levels of commitment among members.

A neutral coordinator is critical for success.

While many professionals strive to set aside allegiance and competition to serve the greater good, for others this is difficult. Hospice contacts noted that while competitors may not think of it or initiate it, they are receptive to meeting together if a neutral convener gathers the group to address a common need.

Sustaining Participation

Stakeholders who are involved with various coalitions and collaborative efforts talked about the challenges of keeping individual and organizational members engaged and participating.

- Fewer resources and heavier workloads stall collaboration simply because it is difficult to coordinate schedules. In the recent past at the Michigan Department of Community Health there was a culture of not working together across units; to support collaboration, this culture must change.
- Frequent turnover in hospice and nursing home leadership leads to a lack of continuity that hampers collaboration.
- Some organizations want to join coalitions but cannot actively support projects. In many groups there is a small core of dedicated individuals who do most of the work.
- Even when organizations commit to work on coalition objectives and to report their activities, there are varying levels of participation and follow-through.
- When a single person represents an organization, it is an ongoing challenge to help that person establish sound communication and sustainable action in the agency.
- Other challenges for collaborative efforts include how to keep members engaged, how to preserve gains after an objective is achieved, and how to sustain activity across gubernatorial administrations.

The coalitions that have maintained full-throttle effort most successfully are those with at least one paid coordinator.

Leadership Challenges

Two leadership challenges emerged—need for a neutral coordinator and incongruity between views of organizational leaders and front line service providers.

Neutral Coordinator—A coordinating agency is critical for end of life efforts, because no single provider organization has the manpower to manage the role. The Michigan Hospice and Palliative Care Organization (MHPCO) has shouldered the responsibility for years, most recently through the Michigan Partnership for the Advancement of End of Life Care. Comments from some Partnership members addressed the issue of neutrality.

One saw the tight link between hospice and end of life as a problem, since meeting the full range of end of life needs requires models of care beyond hospice. Another observed that when people and organizations identify end of life as a hospice niche, they do not see a role for themselves. A third commented that health care organizations will collaborate for quality improvement if the effort is orchestrated for them by a neutral third party rather than by an agency that may be perceived as having something to gain from the outcome. And a fourth remark concerned sensitivity in MHPCO ranks about the possibility of palliative care services diverting patients from hospice. These comments point to the prospect of reduced collaboration for end of life efforts in the state if stakeholders do not perceive the convener to be a neutral organization.

Incongruity of Views—It became apparent in talking with key organizational leaders and with direct service providers that the two groups view the status quo differently.

Two leaders cited strides in cooperation between nursing home and hospice providers, noting that they have for the most part resolved their differences and reached joint understanding about working together. One nursing home leader did not see pain management as much of a problem anymore. These views conflict with reports from hospice contacts around the state that nursing homes still refuse hospice contracts and continue to have problems with correct use of appropriate pain medications.

Another organizational leader observed that physicians are aware of end of life pain management, have a good knowledge base, and use it in practice. The leader also noted that physicians conduct advance care planning conversations with their patients. These views conflict with hospice contacts' reports of the substantial proportion of new patients that are admitted in severe pain and ill-informed about their prognosis and choices.

Systems and Resources

Strengths

Michigan's strengths in systems and resources for delivering end of life care include people, programs, and untapped potential.

Champions: Experts, Leaders, Advocates

A number of nationally recognized experts in end of life care are based in Michigan. They represent diverse disciplines—medicine,

Systems & Resources

Strengths
Champions
Model programs & resources
Untapped potential

Obstacles
Lack of funding
Lack of support services
Frustration with MDCH
Lack of surveillance
Lack of person-centered care
Rural challenges

nursing, ethics, law, palliative care, hospice, bereavement, social work, long term care, and others—and they work and collaborate in academic, clinical, and community settings. These leaders share a passion for and commitment to improving end of life care. Many have toiled for more than a decade to advance the state of end of life care in Michigan.

Together these experts and the growing number of hospice and palliative care professionals and volunteers form a critical mass of end of life advocates. One stakeholder commented that others in the field notice this and find it unusual compared to their states.

Michigan has an unusual number of national experts in end of life care in academic, clinical, and community settings. They represent diverse disciplines.

There also are a number of model programs and resources for:

- Health professional training
- Hospice and pre-hospice services
- Palliative care
- End of life decision-making
- Improved pain control
- Consumer and caregiver education.

Model Programs and Resources
Michigan professionals have developed innovative programs to address needs related to end of life. Some have won national recognition for their excellence, and many have demonstrated favorable outcomes. These are models that could be adopted and adapted for use in more settings statewide. Examples include:

- Academic programs for professional education
- Hospice, palliative care, and pre-hospice services
- State and community coalitions
- Services to support end of life decision-making
- Consumer and caregiver education
- Improving pain management in long term care facilities.

Several of these programs have developed resources that are useful for consumers and professionals. The resources target needs like end of life decision-making, pain and symptom management, caregiver how-to information, collaboration between hospices and nursing homes, and professional education related to end of life.

Untapped Potential
A number of programs target other priorities but offer potential as untapped partners or approaches for enhancing end of life care.

Michigan Cancer Pain Initiative—A 9-month quality improvement project with 23 Michigan hospital, nursing home, and home health providers produced sustainable improvement in agency pain management practices. While the MCPI has been inactive since November 2003, remaining funds are available until March 2006.

Quality Improvement Collaborative—This practical and action-oriented approach to change has helped teams produce rapid and meaningful improvements in end of life care in a variety of settings (Lynn, Schuster, & Kabcenell, 2000). At least one of Michigan's model programs is a product of rapid-cycle change, and Michigan

experts have served as faculty for such collaboratives. The Michigan Hospital and Health Association's Keystone Center for Patient Safety and Quality is using this method now to advance hospital stroke and ICU care, and the Michigan Peer Review Organization has used a similar approach to help nursing homes improve pain management practices. Michigan has the talent to serve as faculty for a local collaborative to generate rapid change to address our critical end of life needs.

Quality improvement collaboratives have produced rapid and important gains in end of life care in varied settings. Michigan has the talent to serve as faculty for such a collaboraborative.

Bereaved Families—Many bereaved families eventually contact hospice asking what they can do to help others. They represent a powerful resource, because they can put a face on end of life issues and help administrators, physicians, and consumers feel the urgency of the needs and the value of hospice and palliative care.

Don Berwick, a leading champion of health care quality, considers the voice of the consumer to be a powerful influence on decision-makers: "We haven't invited patients to speak up enough…It's storytelling; it's hearing that this patient was in my hospital and this is what they went through. We need to create a space for patients to talk about things like that. Because, sooner or later, it's going to be me or my child" (Galvin, 2005).

Primary Care Physicians Dementia Leaders Network—This network of physician dementia leaders is working to educate their peers and to expand access to dementia assessment and care for patients of doctors who feel ill-equipped to provide these services. An approach similar to this evidence-based model may work to expand access to palliative care services for persons whose physicians feel ill-equipped to manage end of life pain and symptoms, especially for those persons who do not qualify for home care or hospice.

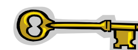
Multidisciplinary Second Opinion Clinics—This innovative project of the Michigan Parkinson Initiative brings assessment services to persons with Parkinson's disease in underserved areas of the state. A similar approach may work to expand access to palliative care consultations for persons in underserved areas.

Nurse-Managed Health Centers—A network of centers provides coordinated, patient-centered primary care for vulnerable populations. The centers achieve excellent clinical outcomes, high patient satisfaction, and low costs. The nurses are skilled at managing care for persons with special needs (like chronic mental illness, for example), and one clinic has demonstrated great success in a capitated contract for primary care for aged veterans. These clinics may be potential partners for end of life care for

underserved populations that are uninsured or have publicly funded health coverage like Medicaid or county insurance plans.

Person-Centered Care—There are several models of person-centered care for vulnerable populations in the state. Assertive Community Treatment (ACT) teams provide multidisciplinary support to help high risk persons remain in community settings in the mental health system. Care managers support person-centered planning and care for persons with developmental disabilities and for persons with chronic mental illness. Bringing the Eden Alternative to Michigan (BEAM) helps nursing homes create a culture that supports person-centered care without straining the facility's resources. All of these programs are potential partners for improving quality of care for clients who have end of life needs.

Partners for Consumer Education—With a neutral sponsor and useful resources, many organizations may be willing to educate their clients about end of life issues. For instance, Area Agencies on Aging can help to raise older adults' expectations about pain and symptom management and informed choice. With appropriate training they might serve as a resource for advance care planning.



Two major obstacles to advancing end of life care in Michigan are lack of funding and lack of community support services.

Lack of funding yields inadequate resources for effective, sustained change. It ties willing hands and limits the scope of projects to affordable pieces rather than comprehensive efforts.

Community support services fill gaps for people who are declining but do not have family caregivers or the means to hire others. When the need for support exceeds the supply of services, people at the end of life are left to fend for themselves.

System and Resource Obstacles

End of life issues rank from high to low in importance among interviewed stakeholders. Those who called it a high priority work in agencies with a mission of service or advocacy for people at the end of life. Those who ranked it medium or low work in organizations that serve a broad constituency, have limited resources, and consider end of life to be less urgent than other operational priorities.

Almost all stakeholders offered opinions about system or resource obstacles to progress in end of life care. They commented about lack of funding for sustained efforts (18 mentions), frustration with the Michigan Department of Community Health (11), inadequacies in tracking end of life issues (8), and lack of person-centered care (7). Comments from hospice providers focused heavily on the lack of community support services for patients and caregivers (37 mentions) and on the challenges of delivering services in rural areas (9).

Lack of Funding

While stakeholders listed many funding foibles, the end result was the same in every case—inadequate resources for meaningful, sustained change. These are the common themes in their comments:

- When there is no funding at all, willing hands are tied and needed changes remain on the wish list. Progress depends upon the energy and enthusiasm of a few key people who eventually wear out.
- When funding is thinly spread over many projects, none have the resources to succeed and sustain.
- When funding time frames are short, worthwhile projects end too soon to achieve full benefit or to collect useful data.
- When grants fund the development of programs but not the manpower to manage them, gains disappear.
- Brief, sporadic efforts don't add up to much. It would be better to choose a few priorities and invest in doing them well.

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When there is no funding at all, willing hands are tied. Progress depends upon the energy of a few people who eventually wear out.

Lack of resources—time and money—limits collaborative efforts. To survive, many agencies must narrow their focus to their own top priorities and forego opportunities to partner on issues less central to their mission. This reality hampers synergistic efforts to address cross-cutting needs that may be compelling for the population but not for every organization.

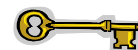
Those who do attempt to collaborate sometimes run out of funded time to achieve their goals. End of life and palliative care projects by nature involve interdisciplinary cooperation, and often it takes longer than expected to gather the group and launch the effort. Given this reality, funding time frames may be too brief.

Lack of resources also prompts a shift in scope from comprehensive strategies to more realistically affordable efforts. Recognizing Michigan's difficult economic climate, statewide coalitions have made strategic choices to stay within their means. For instance the Michigan Dementia Coalition, rather than developing a plan to comprehensively address dementia needs, carefully selected "strategies that were evidence-based, capitalized on existing resources, and could be implemented affordably to create the greatest impact" (Michigan Dementia Coalition, 2003). Dwindling resources also forced the Michigan Partnership for the Advancement of End of Life Care to implement only selected projects in a comprehensive strategic plan.

Some stakeholders commented that providers do not know what funding is available or where to look for it. They also need technical assistance to write grant proposals and to educate foundations about end of life needs.

Lack of Support Services

Thirty-nine percent of hospice contacts from rural and urban counties all over the state raised concern about the lack of support services for patients and caregivers. Many mentioned more than one issue.



People who are declining with life-limiting illnesses and do not have capable caregivers or the means to hire them need more support services than are available or affordable in their communities.

Of the 37 total mentions, 18 concerned the problem of hospice patients that have no able or available caregiver and cannot afford to pay for extra help at home or to move to a nursing home. These persons may live alone or with a frail spouse who cannot provide the needed assistance. They may have working children who cannot provide 24-hour care.

Another eight comments related to people “in the gap” who do not qualify for hospice or home care but have the same intensity of need for services. They commonly are declining with a slowly progressive illness and difficult-to-predict lifespan, and many of them cannot afford private help or nursing homes.

A common factor in all of these scenarios is a lack of community support services. Five contacts cited a shortage of nursing home beds, and five reported limited or lacking options for respite care. Another spoke of an overall shortage of community support. The bottom line is that people who are declining with life-limiting illnesses and do not have capable caregivers or the means to hire them need more support services than are available or affordable in their communities.

Frustration with the MDCH

System and resource obstacles attributed to the Michigan Department of Community Health involved skepticism about the department’s commitment to end of life care (7 mentions) and dissatisfaction with oversight of hospices and nursing homes (4).

Stakeholders who expressed frustration with MDCH commitment have experienced withdrawal of funding and shifts in program priorities when political leadership changed. There is a perception that activity proceeds in fits and starts and that promising efforts are launched and then fizzle without achieving desired outcomes.

In a few cases stakeholders’ skepticism grew from apparent misconceptions about the MDCH. For example, some criticized the department for withdrawing support for projects that were funded by other sources and spearheaded by other agencies. Other critics received MDCH funding for projects through a fiscal intermediary and may have been unaware of the connection.

The stakeholders who expressed dissatisfaction with MDCH oversight of hospices and nursing homes were concerned about the survey process. Oversight for nursing homes was seen as contentious, punitive, and working against a culture where residents can get effective pain and symptom management at the end of life. Oversight for hospices was described as delayed, infrequent, contentious, and inconsistent (surveyors interpret regulations differently).

Stakeholders are skeptical of the level of commitment to end of life by the Michigan Department of Community Health. There is a perception that support for promising efforts fizzles before outcomes are achieved. Some of the skepticism is based upon misconceptions.

Periodic inspections are not federally mandated for hospices (Petrisek & Mor, 1999), but some contacts think they should be. Two noted that their own agencies have not been surveyed for years; for one it has been more than a decade. Their concern was that without external accountability, some agencies may slip in quality of care and integrity of business practices. Both cited evidence that this has begun to occur. Currently hospice surveys are conducted according to state priorities and resources; the focus in Michigan has been new licensure and complaints.

Lack of Surveillance

All providers who care for persons at the end of life collect information about their clients. Many track indicators of program services and outcomes, but no agency or organization compiles all of that data to monitor end of life needs and services in the state.

Hospice—In an attempt to track annual hospice utilization, the Michigan Hospice and Palliative Care Organization (MHPCO) collects data from state hospices and reports it to the national organization. However participation is voluntary, and only about one third of Michigan agencies contributed data in 2002. Not all hospices are equally prepared to extract and analyze this information and not all of them monitor the same indicators. For instance some track the median length of service and others track the average; some track the proportion of clients with lengths of stay of 7 days or less, while others track stays less than 10 or 14 days. With annual membership renewals MHPCO does collect data on the number of clients served the prior year. Currently there is no reporting of hospice quality indicators, but the new Medicare conditions of participation will require this.

Palliative Care—There is no common data set or organized tracking of data on palliative care or pain management programs in Michigan—for instance, scope of services, volume served, outcomes. Most of the existing inpatient palliative care programs have begun to track self-defined indicators, but it is difficult to compare one program with another or to determine the penetration

and impact of palliative care statewide. Even if they did track the same indicators, the programs use different information systems to do so.

There is no system for monitoring end of life service needs, outcomes, and progress for the Michigan population. Relevant data is collected by many providers but not centrally compiled. There is partial information about hospice services and no tracking of data on palliative care programs or end of life services in nursing homes.

Nursing Home and Home Health—Nursing home and home health assessment data are reported to Medicare and Medicaid via the Michigan Department of Community Health, but there currently is no organized monitoring or reporting of end of life indicators. The MDCH does monitor 24 quality *indicators*; these differ from the 10 quality *measures* (including pain) that are tracked by the federal Centers for Medicare and Medicaid Services (CMS). Nursing home data must be interpreted with caution because of inconsistencies in data collection across facilities. CMS has launched an initiative to assess and validate data from the required Minimum Data Set (MDS).

One item on the MDS indicates whether the resident receives hospice care. Nursing home surveyors also record the number of hospice beneficiaries on the day of the inspection visit (Petrisek & Mor, 1999), but this data has not been compiled in Michigan to monitor availability of services to nursing home residents.

Special Populations—For special populations end of life issues may be assessed but not easily reported. For persons with chronic mental illness, for example, each community mental health provider enters a narrative summary when a client is discharged. It tells the reason for discharge, including death, but notes are difficult to extract from narratives for tracking purposes. And providers use different information systems for storing and reporting data.

Clients in the MI Choice waiver program are assessed using a modified MDS tool, but the data is not analyzed to determine what proportion of clients die and whether or not they utilized hospice services. A stakeholder from a visiting physician practice reported that death seems to be one of the three most common reasons for discharge, but the practice does not have the resources to track and analyze this indicator. Overall, the lack of central monitoring of end of life indicators leaves many unanswered questions about people's end of life experiences in various care settings.

Lack of Person-Centered Care

Stakeholders reported a lack of coordination among providers of care for persons with reduced life expectancy due to advanced illness. They cited scarce resources and facility-based funding as primary reasons. Each setting for care—hospital, nursing home,

home health, waiver program, etc—has different intake sources, criteria, and funding and there is no central point of access. Although there are employees in all of the settings with case manager titles, their roles are limited to managing care in their own agencies and easing transition to the next setting.

The course of decline at the end of life may be punctuated by repeated inpatient stays, but no one looks at the big picture to manage overall care. This scenario is familiar for persons with non-cancer diagnoses like congestive heart failure or chronic lung disease.

Without person-centered care, patients and their families have no advocate to explain prognosis and ensure informed choice about treatment goals and preferences.

The course of decline at the end of life may be punctuated by repeated cycles of acute exacerbation, emergency room visit, inpatient admission, home care, discharge from home care, and then back to the hospital with the next acute episode. When needs are handled setting by setting, no one looks at the big picture to manage overall care. Without person-centered care, patients and their families have no advocate to explain prognosis and ensure informed choice about treatment goals and preferences. Often they do not understand the significance of repeated inpatient stays. This scenario is familiar for persons with non-cancer diagnoses like congestive heart failure and chronic lung disease.

Given a choice about treatment preferences, many people nearing the end of life opt to stay home with help. Long term care advocates pointed out that most Medicaid long term care dollars are earmarked for nursing facility room and board with little available for home-based services and hospice. They see a need to shift more funding toward home- and community-based care and believe that increased access to hospice would improve person-centered care for the long term care population at the end of life.

Rural Challenges

Nine hospice contacts from rural counties discussed the challenges of providing health care in those areas and pointed out issues that are significant for hospice:

- Overhead costs are higher because of the need for more offices, more personnel, and more travel in large service areas. But Medicare hospice reimbursement rates are lower because they are partly based on the local wage index, which is lower in rural areas.
- Rural pharmacies are few and far between, do not always stock needed drugs, and are not open all day every day.
- In many areas the need for community support services exceeds the supply.

Providers and Consumers

Providers & Consumers

Strengths
Hospice teams
Local clinician champions
Palliative care teams
Bereaved family members

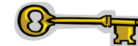
Obstacles
Physician
Nursing home
Consumer

Strengths

Among Michigan's most visible assets for improving end of life care are the providers and volunteers who work daily to make hospice and palliative care available when needed. This group includes hospice teams, local physician champions, palliative care teams, and bereaved family members.

Hospice Teams

The 146 hospice agencies in Michigan work constantly all over the state to raise awareness of hospice services among consumers and health professionals. They reach out to their communities through educational presentations and other events, often after work hours. Hospices open their grief support programs to all bereaved individuals in the community whether or not they have a hospice connection. They also reach out to professional partners like physicians, parish nurses, nursing homes, and faith communities and provide training to help them understand hospice services and identify persons who can benefit. Many hospices have developed innovative methods for provider and consumer education that they are willing to share with others. Hospice professionals of all disciplines along with the 8000+ volunteers that support them comprise an impressive and responsive legion of advocates for end of life issues in the state.



Hospice and palliative care teams, physician champions, and volunteers comprise a critical mass of advocates for end of life care. And bereaved family members who eventually wish to share their stories can help physicians and peers feel the impact of hospice and consider it for their own patients and families.

Local Clinician Champions

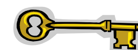
The doctors, nurses, and other providers in Michigan who hold end of life or palliative care certifications are another important force. As pioneers in an emerging specialty they are uniquely qualified to train and mentor their peers to improve end of life decision-making and pain and symptom management. Along with hospice medical directors and other clinicians who have cultivated expertise in end of life care, they represent a key resource for local consultation and training to advance end of life care.

Palliative Care Teams

The physician/nurse practitioner teams that launch inpatient palliative care programs improve awareness of and skills in palliative care in the hospital setting. Along with clinical expertise they model collegial physician/nurse collaboration and in some instances trigger a change in the facility's culture of care. They are mentors for peers who start inpatient palliative care services in other communities.

Bereaved Family Members

The staunchest hospice advocates are people who have experienced hospice services firsthand for their loved ones. After working through their grief many family members approach hospice asking how they can help. Some become volunteers. Their personal stories are invaluable in helping others—both physicians and consumers—feel the impact of hospice and consider it for their own patients and families. These family survivors and their stories are an untapped resource for the advancement of end of life care in Michigan.



Of 53 hospice contacts, 80% noted problems with physicians in their areas:

- 70% said physicians lack knowledge of pain management.
- 57% said physicians are uneasy with end of life discussions.

Of those who noted these problems, 50% said that doctors resist continuing education about end of life care.

Provider and Consumer Obstacles

The two most common themes that surfaced as stakeholders and hospice contacts talked about provider barriers to end of life progress were problems related to physicians (53 mentions) and long term care providers (34 mentions). There were 32 mentions of consumer obstacles.

Physician Obstacles

Stakeholders and hospice contacts shared three common concerns about physician practice patterns related to end of life care:

- Lack knowledge about pain management, resulting in undertreatment of pain.
- Uneasy with talks about end of life needs and planning.
- Reluctant to switch from curative to palliative treatment.

Lack Knowledge about Pain Management—Of 53 hospice contacts who commented about obstacles to progress in end of life care, 80 percent mentioned at least one physician obstacle. The most common one, mentioned by 70 percent, was lack of knowledge of pain management. Cancer pain was most often the focus, and knowledge was lacking about opioid drugs and dosing and about drugs for relief of bone and nerve pain. Half of the hospice contacts who noted this problem also reported that physicians resist continuing education about hospice and end of life care.

Uneasy with End of Life Discussions—This problem was mentioned by 57 percent of hospice contacts. One stakeholder commented that there is pervasive discomfort with facing and talking about end of life and suggested that doctors need tools to help them know who to talk with, how, and when. Other contacts mentioned that doctors lack the time to facilitate the conversation. Half of hospice contacts reported that both pain management and end of life discussions were problems with physicians in their areas.

Treat beyond Benefit—One third of hospice contacts noted that certain oncology practices in their areas seemed to give aggressive treatment to patients beyond the point when any curative benefit could be expected. One contact commented:

> *Lots of the issue for doctors is a personal struggle. It is difficult to give up the fight and hard to have the end of life conversation.*

Physicians commented that with a growing arsenal of chemotherapeutic agents, doctors can treat further into the illness if only to palliate symptoms. However hospice contacts noted that if treatment was intended to relieve symptoms rather than to cure, in many cases the patient and family had not absorbed that message.

Resist Continuing Education—One third of hospice contacts noted that physicians in their areas had not been receptive to continuing education sessions about hospice and end of life care. Some doctors were not interested in using opioids or in learning about them. A hospital stakeholder noted that all of health care has difficulty adopting new evidence-based practices.

"Some doctors treat patients to death with repeated infusions and never give the patients a hint that they have a choice. Many people are tired and just want to be comfortable; that's a choice too. For example, one 97 year- old was treated with six weeks of aggressive therapy for lymphoma without being offered any other choice. There is a HUGE need for education that you have a choice and how to understand the information you get."

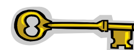
Nursing Home Obstacles

Stakeholders and hospice contacts alike raised many concerns about the challenges that nursing homes face in providing end of life care. The majority of their concerns related to access to hospice care (17 mentions), quality of end of life care (12), and staffing issues (5).

Restricted Access to Hospice—Nursing homes are not required to contract with hospice and some refuse to do so. Hospice contacts in many areas observed that nursing homes are more likely to accept an occasional hospice admission than to refer existing residents for care. Data for 2002 indicate that only 1 of every 4 nursing home decedents that year received hospice care (see Table 5.2, p. 60). When they do treat nursing home patients, hospice team members encounter resentment from facility staff members who do not recognize the value added by hospice.

In some areas hospices encounter shortages of nursing home beds when a person needs to be admitted. And all hospices encounter the Medicare policy barrier that restricts hospice access for short stay nursing home residents by requiring them to pay the full cost of room and board if they choose hospice care.

Variable Quality of Care—Stakeholders reported that nursing homes vary in their ability to provide quality care and in their capacity and willingness to participate in state- and Medicare-sponsored quality improvement programs. While some facilities have high or medium success with quality improvement, others struggle to provide basic care and lack resources to improve. The MDCH has collaboratively developed and distributed guidelines for pain management and end of life care in long term care facilities, but with staff turnover and limited resources not all sites follow or even read them. These realities make it tough to roll out best practices with nursing homes.



Nursing homes vary in their ability to provide quality care and in their capacity and willingness for quality improvement. End of life care varies in quality too.

Well-meaning staff members who care for dying residents according to rules for rehab patients may unintentionally increase their suffering.

Access to palliative care is limited; only about 1 in 4 nursing home decedents receives hospice care.

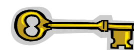
As a result, quality of care for dying residents varies among facilities. Federal regulations mandate preservation of optimal well-being of residents as a quality priority, and state surveys monitor compliance with the regulations. This system drives nursing facilities to maximize residents' activity and intake and minimize the use of drugs that may affect their alertness (like pain medications). While this focus may protect residents who need rehabilitation, it intensifies suffering for those who need palliative care and comfort. The MDCH guidelines for pain management and end of life care address this conflict and clarify an approach to care that meets federal regulations as well as residents' needs. Facilities that cannot or do not implement the MDCH guidelines may unintentionally provide care that reduces quality of life for their residents at the end of life.

A 1999 study of pain levels in terminally ill residents in Michigan nursing homes found that 40.6 percent suffered daily severe pain. Many hospice contacts and most stakeholders who work with nursing homes reported problems with pain assessment, treatment, and monitoring. In some facilities medical directors lack knowledge of pain management and are unwilling to order appropriate medications, and nurses who are unfamiliar with appropriate protocols are reluctant to administer the drugs. One stakeholder noted that nursing home staff may not fully understand end of life care, equating it only with having an advance directive.

Staffing Challenges—Nursing home personnel work hard under very difficult circumstances. Low staffing levels and high turnover are two examples. Minimal staffing makes it difficult for many facilities to meet the intense needs of frail residents who require time-consuming assistance with daily activities like feeding, toileting, and moving or whose medication regimens demand precise timing for successful control of symptoms. Turnover at the direct care level makes it difficult to keep a workforce trained in

pain management and end of life care, while turnover in leadership positions can result in loss of end of life and quality improvement champions.

Two stakeholders expressed concern about the declining supply of nurses due to attrition in an aging workforce and to a shortage of nursing faculty nationally. Another pointed to the shortage of long term care workers due in part to low wages and difficult working conditions. Both of these existing shortfalls are projected to become crises in coming decades as the population ages and requires more care.



Americans deny death as a natural part of life. They resist thinking or talking about it. So it is hard to educate them about end of life.

Many consumers don't know about hospice or have misconceptions about what hospice does.

There is a need to reframe end of life so people can talk about it, and education should address fears and feelings as well as facts.

Consumer Obstacles

The 32 mentions of consumer obstacles to progress in end of life care centered on three issues: cultural denial of death (8), lack of awareness of hospice (6), and misconceptions about death and hospice (18).

Denial of Death—Stakeholders and hospice contacts agreed that Americans deny death as a natural part of life, resist thinking or talking about it, and therefore are hard to educate about the topic. There was a sense that end of life needs to be reframed so people can talk about it. For instance, one hospice has found that middle aged adults are willing to learn about end of life issues as potential advocates for their parents. Stakeholders suggested the value of a celebrity champion who would share a family experience and advocate for advance planning and informed choice.

Misconceptions and Lack of Awareness—Six hospice contacts pointed out that people still don't know what hospice is, what hospice does, who qualifies, and how hospice differs from home care. One commented that this is true over the entire service area of southeastern Michigan. There were 18 comments about a variety of misconceptions that consumers hold about death and hospice:

- People have an unrealistic image of what death is like from media portrayals and from lack of personal exposure.
- People have unrealistic expectations for the success of treatment and resuscitation.
- People see hospice as halting treatment and giving up hope and as a signal of imminent death.
- African Americans may mistrust the health care system and see hospice as a way of withholding curative treatment.
- People think they should save hospice until the very end; they fear morphine, dying, and giving up hope.

All of these issues point to a need for consumer education that addresses fears and feelings as well as facts about end of life and hospice. Table 10.1 summarizes strengths of and obstacles to end of life progress in Michigan.

Table 10.1. Efforts to Improve End of Life Care in Michigan: Strengths and Obstacles

Policy & Advocacy	Strengths	End of life statutes Advocacy skills Receptive policy-makers
	Obstacles	Policy without action Persistent policy barriers Political roadblocks
Collaboration & Leadership	Strengths	Benefits of collaboration Neutral leadership
	Obstacles	Competition Sustaining participation Leadership challenges
Systems & Resources	Strengths	Champions—experts, leaders, advocates Model programs and resources Untapped potential
	Obstacles	Lack of funding Lack of support services Frustration with MDCH Lack of surveillance Lack of person-centered care Rural challenges
Providers & Consumers	Strengths	Hospice teams Local physician champions Palliative care teams Bereaved family members
	Obstacles	Physician obstacles Nursing home obstacles Consumer obstacles

Lessons Learned

Stakeholders who coordinate state and local coalitions related to end of life and stakeholders who lead organizations that participate in those coalitions articulated a common set of lessons learned from their experiences. They listed the compelling benefits of multi-agency collaboration—leveraging scarce resources, tackling problems that no agency can handle alone, gaining joint insight about each realm's mandates and needs, building relationships, and partnering to help clients. They also identified critical features of effective collaboration and key strategies for sustained success.

Collaborative efforts are most effective when they are action-oriented and focused on a few key priorities. Adequate resources and a neutral convener are critical for success.

Compelling stories and facts help people first feel and then see the need for change and ignite them to act. By working together they achieve more than any single agency can.

Relationships that grow among participants enable partnering during and beyond a project.

Features of Effective Collaborative Efforts

Ignited—Compelling stories help people first feel the need for change and compelling facts help them see it.
Purpose-Driven—Action is driven by what needs to be done rather than by where the dollars are.
Laser-Focused—Goals are limited to a few priorities that offer maximum impact. They serve as a road map for action.
Action-Oriented—Active participation is expected of members and defined to include committing to goals, acting to achieve them, and reporting progress.
Purposeful—Members are recruited based upon their diversity of expertise and potential contributions to priority objectives. They are invited to play a particular role based upon their strengths, resources, and constituencies.
Sustained—Projects are built to last over time rather than being dependent upon people staying fired up to continue.

Key Strategies for Sustained Success

- The collaboration is guided by a neutral convener—a credible organization and trustworthy person with no perceived gain from advancing the cause.
- The goals are cross-cutting. They appeal to people in different settings with similar concerns that don't lend themselves to an easy solution by any single provider.
- Members are organizations and they are represented by decision-makers. This brings more potential funds, time, and effort to the cause.
- Resources are critical. Funds and staff enable action and achievement.
- The member role and expectations are defined. Otherwise people may give little simply because they do not know what to do. Different levels of involvement are offered.

- There is a focus on building relationships among members. Project staff can help members see opportunities for collaboration that they may not identify on their own.
- Territorialism and posturing are anticipated, even though there is an ethic of setting aside competition and personal gain for the greater good. Leaders plan strategies to deal with particular people or issues.
- Meetings occur often enough to keep the momentum going.
- A plan and perseverance generate cultural change, often in small steps over time. Flexibility is essential so regions and organizations can adapt an approach to their needs.
- Progress is measured. Members are accountable for reporting their efforts.
- An infrastructure is created to maintain gains and to support the people involved.
- Successes are recognized and celebrated. Positive outcomes build credibility for future efforts.
- Policy makers are updated and educated regularly to build and nurture mutually supportive relationships.

Implications for Policy and Programs

Michigan's strengths in the end of life arena are many:

- Laws that support informed choice and pain control
- Collaborative partnerships to improve end of life care
- A critical mass of expert and persevering champions
- A variety of model programs and resources.

Coalitions and partnerships and individual providers toil independently but face universal obstacles—policy roadblocks, lack of resources, system barriers, competing constituents, and resistant target groups—that none can conquer alone.

Conduct a Sustained Campaign

Michigan's three critical end of life needs are cross-cutting issues. There has not been a coordinated, sustained, statewide effort to address any of the needs. The time is right to choose a priority and orchestrate such a campaign. It will be most effective if it:

- Engages organizations and champions that represent service providers, state and community partners, and special populations.
- Links established statewide efforts.
- Capitalizes on existing policy, system and provider strengths and applies lessons learned from prior efforts.

- Fosters exchange and adoption of proven models and resources for service delivery, provider training, and consumer education.
- Supports regional adaptation and variation.
- Employs health education and health behavior change theory to tailor interventions for multiple target groups.
- Promotes economies of scale by coordinating joint trainings and technical assistance for agencies to facilitate the adoption of key strategies.
- Establishes and tracks indicators to measure progress.

An effective approach is three-pronged. One targets consumers to raise their expectations for quality end of life care and build skills to demand it. A second facilitates training for providers and a third supports process changes to make it easier to do the right thing.

Extend Use of Promising Practices

Successful strategies for addressing the three critical end of life needs already have been developed and used by Michigan hospices, palliative care programs, hospitals, home care agencies, nursing homes, and other organizations. Enlisting more agencies to use these strategies is a reasonable step to advance end of life care. Providers now consult with one another informally for advice and technical assistance (for instance, how to start an inpatient palliative care program), but they can be convened as a network to exchange practices and learn from each other more efficiently.

Facilitate Rapid Change

The rapid cycle change method has been used successfully by teams in Michigan and nationwide to improve quality of care in a variety of settings. It is a practical and action-oriented approach and is an appropriate way to expand use of promising practices to address critical end of life needs. Michigan has enough talent to serve as faculty for a quality improvement collaborative.

Educate Foundations

A neutral convener may facilitate access to resources to support extended activities by educating Michigan grant makers about statewide end of life program and funding needs and by providing technical assistance and templates for local funding requests.

Mobilize Champions

There are many end of life champions within communities who may not be active at the state level but may contribute locally if approached with a specific request. As a group they could be a powerful statewide network.

Adapt Promising Models

When necessary, successful program models developed for other purposes may be adapted to address end of life needs. For economies of scale, a single entity can develop resources that will be needed to address common problems statewide—for instance, a statewide media campaign or training programs.

Address MDCH Issues

A particular implication for the Michigan Department of Community Health is to address the internal policy and procedural obstacles perceived by stakeholders and hospice contacts.

Boost Momentum

Dr. Kevorkian's actions made it clear that people who are suffering or wish to avoid it may resort to desperate measures when there seems to be no alternative. The defeat of the 1998 ballot proposal to legalize assisted suicide generated commitment to offer better options, and there have been many positive policy changes as a result. But medical practice has not changed much. People are still not fully informed about their treatment options, and they continue to suffer needlessly at the end of life.

Health care professionals with skills in hospice and palliative care do talk with people and their caregivers about end of life goals and choices and do treat their pain and symptoms. But too many other providers avoid candid conversations and accept suffering in persons with advanced illness. Gains in these areas will benefit both persons who are dying and their caregivers.

Despite a commitment to offer alternatives to assisted suicide, there has been no effective campaign to educate the population about their rights to informed choice and effective pain control. There has been no effective campaign to help providers embrace the need and skills to talk candidly with patients about end of life choices and to use proven protocols to treat their pain and other symptoms. But many pieces exist for both campaigns.

The persistent efforts of Michigan's hospice and palliative care community, despite limited resources and other obstacles, have yielded a rich supply of proven interventions and promising resources. It is time to boost the momentum of change with a focus on action to spread the innovations statewide and ensure informed choice and humane treatment for more residents. Michigan has the opportunity to earn another turn in the end of life spotlight, this time as the state with humane and widely available alternatives to ensure a peaceful ending.

Key Points

Michigan's end of life strengths include laws that ensure informed choice and pain control, collaborative partnerships, champions and nationally recognized experts, and model programs and resources.

Obstacles to improvement in end of life care include policy change without action, lack of resources, system barriers, and resistant target groups.

Collaboration is strong for end of life projects, but it can be tough to maintain for many reasons. A neutral coordinator is critical for success.

Brief, sporadic efforts don't add up to much change. It is more fruitful to choose a few priorities and invest in doing them well.

Community support services fill gaps in care for people who are declining but do not have able caregivers or the means to hire others. Lack of support services is a major obstacle to progress in advancing end of life care.

Nursing homes vary in their ability to provide quality end of life care and in their capacity and willingness for quality improvement. Access to palliative care and hospice is limited.

Consumers deny death and resist education about hospice. End of life needs to be reframed so they can talk about it. Education should address fears and feelings as well as facts.

Bereaved family members who wish to share their stories are a powerful resource. Their compelling stories help decision-makers and others feel the need for change and then compelling facts help them see it.

Michigan needs a sustained and comprehensive campaign to improve pain control and informed choice. The campaign should link existing efforts, foster rapid adoption of proven models, support regional variation, and promote economies of scale.

An effective approach to change is three-pronged. One targets consumers to raise their expectations for quality end of life care and build skills to demand it. A second facilitates training for providers and a third supports process changes to make it easier to do the right thing.