MICHIGAN’S PALLIATIVE CARE CLIMATE
A REPORT ON QUALITY OF LIFE AND PATIENT-FOCUSED HEALTH CARE IN MICHIGAN
# Table of Contents

- Executive Summary .................................................................................................................. 2
- Introduction ............................................................................................................................ 3
- Workforce Development ......................................................................................................... 4
- Palliative Care and the Family ................................................................................................. 5
- Home Care ............................................................................................................................. 5
- Access to Medication ............................................................................................................... 6
- Solutions .................................................................................................................................. 7
- Conclusion .............................................................................................................................. 9
- Acknowledgement .................................................................................................................. 10
- Bibliography ............................................................................................................................ 11
Executive Summary

For the past two years, palliative care providers, policymakers, and patient groups have been reviewing Michigan’s palliative care climate and developing recommendations to improve the delivery of this type of care.

Currently, health systems and providers throughout Michigan offer palliative care in a variety of ways and through several different avenues. Some palliative care programs have teams; some just have one individual providing the services. Reimbursement for these services varies.

Additionally, there are not enough trained palliative care providers to meet patients’ demand for this type of service. This is due in part to a lack of formal training programs available for health care providers, as well as inadequate funding for these programs.

There is also a lack of patient education on the availability and benefits of palliative care, as well as insufficient tools to help patients decide whether this care is right for them and their families. This report focuses on four topic areas:

- Workforce Development
- Palliative Care and the Family
- Home Care
- Access to Medication

As a result of our discussions, we developed the following policy recommendations:

- Create a Michigan Palliative Care Commission;
- Appoint palliative care providers to Michigan’s Prescription Drug and Opioid Abuse Commission;
- Develop a legislative task force to review health care decision-making tools and MI-POST laws;
- Secure funding for palliative care provider training;
- Update insurance code to provide coverage for palliative care teams; and
- Fund a pilot project for palliative care team reimbursement.
Introduction:

Palliative care is a service that’s been offered by health professionals around the country since the 1970s. There exists a popular misconception that palliative care is the same as hospice or end-of-life care. While palliative care may encompass those types of services, it means so much more. Palliative care is appropriate at any age and any stage of a serious illness and can be provided alongside curative treatment. The Center to Advance Palliative Care defined palliative care in its 2015 state-by-state report card as the following:

“Palliative medicine is specialized medical care for people with serious illnesses. It focuses on providing relief from the pain, symptoms and distress of serious illness. It is a team-based approach to care involving specialty-trained doctors, nurses, social workers and other specialists focused on improving quality of life. By determining patients’ goals of care through skilled communication, treating distressing symptoms and coordinating care, palliative care teams meet patients’ needs and help them avoid unwanted and expensive crisis care. Unlike hospice care, palliative care can be provided at the same time as curative treatments; it is appropriate at any age and at any stage of a serious illness.” (R. Sean Morrison, 2015)

In this report, on a grading scale of A to F, Michigan scored a grade of “B”. Among Michigan’s neighbors, there were only two states that received an “A” grade: Ohio and Wisconsin. As noted in the chart below, there are currently 48 total palliative care programs in Michigan out of 72 hospitals. In 2011, there were 65 programs out of 85 hospitals, illustrating a decrease in available palliative care programs. A developing area of palliative care is outpatient palliative care services, which currently lacks a wealth of data. A 2011 study, which looked at California hospitals, showed that most outpatient palliative care services are new and half were established in the past half year (Berger, 2011). They typically follow national guidelines with interdisciplinary teams that have nurses acting as the core providers (Berger, 2011).

<table>
<thead>
<tr>
<th>State</th>
<th>Letter Grade</th>
<th>Grade</th>
<th>Total Programs/Hospitals</th>
<th>By Hospital Type (≥ 50 beds)</th>
<th>Sole Community Provider (≤50 beds)</th>
<th>&gt;300 beds</th>
<th>&lt;50 beds*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Nonprofit</td>
<td>For-Profit</td>
<td>Public</td>
<td></td>
</tr>
<tr>
<td>Illinois</td>
<td>B</td>
<td>72.1</td>
<td>(75/104)</td>
<td>75% (71/95)</td>
<td>40% (2/5)</td>
<td>50% (2/4)</td>
<td>40% (2/5)</td>
</tr>
<tr>
<td>Indiana</td>
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<td>67.7</td>
<td>(44/65)</td>
<td>79% (34/33)</td>
<td>38% (3/8)</td>
<td>50% (7/14)</td>
<td>50% (2/4)</td>
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<tr>
<td>Michigan</td>
<td>B</td>
<td>66.7</td>
<td>(48/72)</td>
<td>67% (41/61)</td>
<td>100% (5/5)</td>
<td>33% (2/6)</td>
<td>40% (4/10)</td>
</tr>
<tr>
<td>Ohio</td>
<td>A</td>
<td>82.8</td>
<td>(82/99)</td>
<td>84% (76/90)</td>
<td>100% (2/2)</td>
<td>57% (4/7)</td>
<td>67% (4/6)</td>
</tr>
<tr>
<td>Wisconsin</td>
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<td>87.7</td>
<td>(50/57)</td>
<td>98% (49/56)</td>
<td>100% (1/1)</td>
<td>– (0/0)</td>
<td>100% (4/4)</td>
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<tr>
<td>EAST NORTH CENTRAL</td>
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<td>75.3</td>
<td>(299/397)</td>
<td>79% (271/345)</td>
<td>62% (13/21)</td>
<td>48% (15/31)</td>
<td>55% (16/29)</td>
</tr>
</tbody>
</table>

(R. Sean Morrison, 2015)
The American Cancer Society Cancer Action Network (ACS CAN) identified challenges surrounding palliative care awareness and delivery in Michigan and took action. In March 2015, ACS CAN organized a policy summit to address these issues. ACS CAN invited health-care workers and policymakers from throughout the state to work together to create a roadmap to improve palliative care awareness and delivery.

Members from several health systems, universities, government agencies, patient groups and others participated in the discussion. During the first meeting, they identified four areas of focus including:

- Workforce Development;
- Palliative Care and the Family;
- Home Care; and
- Access to Medication.

The group was charged with developing principles that could be used to guide the creation of public policy, as well as internal policies for insurers and health-care providers. These recommendations are described below by issue area.

**Workforce Development**

The group identified workforce development as the topic that most needed the state’s attention. The means and method of providing palliative care varies from health system to health system. Palliative care providers are a very diverse group of professionals, but there are not enough of them to meet the current demand for these services.

Several questions guided the group’s discussion on workforce development and palliative care: what does a quality program need; what are some examples of quality programs; what or who should be included in the models; do the models change between settings, and if so, how.

Overall, there is a shortage of health-care providers in the palliative care field in Michigan. There were only 10 fellowships for palliative care providers in 2015. Certification in hospice and palliative nursing is available through the Hospice and Palliative Credentialing Center at the levels of advance practice nurse, registered nurse as well as nursing assistant. However, there is a lack of resources and financial support to train health care providers in palliative care and without adequate funding these barriers to training are unlikely to improve.

Given the palliative care needs of the aging, chronically ill population, all health care providers should be trained to provide generalist palliative care with knowledge and skills related to basic pain and symptom control, advance care planning, and referral to resources for advanced palliative care. This education needs to be integrated into the curriculum for all providers with opportunities for ongoing continuing education.

Finally, another area where there can be development is in communication and coordination between health care providers. Inconsistent communication and coordination leads to unnecessary roadblocks to care or coverage and misunderstandings between caregivers and providers. Regular correspondence between all parties is a key component of quality palliative care.
Palliative Care and the Family

Palliative care is a term that is not only new for most patients, but for family members as well. Chronic conditions, such as cancer, can generate many questions and challenges for both patients and their caregivers. Palliative care generalists and specialists must be available to answer these questions, improving quality of life for both the patient and his or her family.

Palliative care is not synonymous with end-of-life. This misnomer is due to a lack of available information for patients and family members on palliative care. Because different health systems offer palliative care in different ways, there is a variance in what information families receive on these services.

Making health-care decisions on behalf of a loved one is difficult in its own right, but some family members and patients are not familiar with the resources and programs available to support such decision-making. Changes are necessary to make these tools more accessible and easier to understand, while protecting the rights and wishes of the patients.

Michigan would benefit from a coordinated effort to increase education and awareness of available resources when a loved one is unable to make health-care decisions on their own. Power of attorney laws and other health-care decision-making tools are frequently a foreign language for family members, leaving them confused, frustrated, and possibly lowering the quality of care.

Home Care:

Most patients today want to be home, if they can, and studies have shown that home care is cost effective. One study found that subjects who were on Medicaid and receiving care at home were able to receive that care at 40 percent of what it would have cost in a nursing facility (Wiener, Spring 2002). Home care is one arena where palliative care is beginning to develop, but more needs to be done. A California study showed that outpatient palliative care services improved the continuity of care, reduced rehospitalizations, and resulted in improved patient outcomes (Berger, 2011). Therefore, it is important to start establishing outpatient palliative care services composed of interdisciplinary teams that follow the national guidelines that have been set.

Health insurance traditionally does not cover at-home palliative care services. If there is coverage it only covers consultative services of a physician or advance practice nurse. Patients and families often need comprehensive assessment and support provided by an interdisciplinary team which may include skilled nursing staff, social workers and chaplains in addition to the palliative care provider. Current reimbursement structures often do not cover these beneficial interdisciplinary teams. These are only a few examples of care providers who do not receive any reimbursement for the services under current reimbursement for outpatient palliative care.

Many patients designated as “homebound” are eligible for palliative care services. Frequently, this happens through hospice care, but there are many reasons why a patient would be homebound for a period but not require hospice services. “Homebound” needs a broader definition, so that these patients could receive reimbursement for at-home palliative care. Many patients who would benefit
from palliative care do not meet the “homebound” criteria required to access a home care benefit. This presents a significant challenge to meeting the needs of patients living with serious illness who prefer to be at home and need support in managing distressing symptoms but are not so ill that they are “homebound”, nor ready/eligible for hospice care.

For example, insurance plans will generally cover a triage nurse for hospice patients who is on-call 24 hours a day. Palliative care patients may need a triage nurse as well if they’re recovering from a major surgery or procedure. This can help keep a patient from returning to the hospital and increasing the cost of their medical care. Patients and families can also benefit from a social worker to help them access additional financial, healthcare or personal resources.

As telemedicine continues to evolve, more patients are able to receive care though this service than ever before. This is an emerging way to provide quality palliative care without patients having to travel long distances to receive it. The Veterans Affairs Administration has adopted the use of telemedicine for palliative care, and now, veterans both statewide and nationwide can more conveniently access these services. However, Michigan’s use of telemedicine continues to lag behind.

Home care can provide quality palliative care in a cost-effective setting for both patients and providers. But only a few states are currently offering reimbursement for home-based palliative care and services for as long as the patient may benefit. The services cannot be time-bound. Michigan has an opportunity to create a pilot program to see how effective these services could be and assess the overall cost-savings.

**Access to Medication:**

Palliative care is, by definition, care of the whole patient. This includes managing the symptoms that accompany their care, like pain. Nationwide, the use of controlled substances to manage pain has increased. In 2012, Michigan reported a startling increase in the number of prescribed opioids.

As concern over substance abuse and addiction has entered the media spotlight, many state policymakers have taken a closer look at laws and regulation related to prescription opioids. Pain management is an important component of palliative care and opioids need to be available to help control pain for those with serious illnesses like cancer. There is concern that new policies regulating prescription opioids may lead to decreased access to these needed pain medications. The study group understands that there needs to be balanced control of opioids but also warns that regulations that restrict access can have a negative impact on the quality of care provided to those with serious illnesses.
Solutions:

Palliative care can provide the all-encompassing care that patients want and loved ones appreciate. Through our discussions, we created the following policy solutions to improve palliative care awareness and delivery:

Workforce

- Increase the number of palliative care professionals in health systems through:
  - Reimbursement incentives for palliative care programs;
  - Increased fellowship positions to train physicians in palliative care;
  - Integration of generalist palliative care into all healthcare provider curricula.
- Create palliative care teams within each health system. The Veterans Affairs Administration hospital systems have embraced the team approach to palliative care. Private health systems should adopt this model as well. Team members may include but not be limited to:
  - Physicians
  - Advanced Nurse Practitioners
  - Nurses
  - Social Workers
Clergy / Religious Leaders

- Expand training programs for health providers in palliative care.
- Create billing codes for palliative care as a specific, reimbursable service.
- Offer incentives to health systems that produce or expand the use of palliative care teams.

Palliative Care and the Family:

- Include family members in the palliative care process:
  - Education to provide family members with a better understanding of what palliative care is and what its goals are;
  - Financial assistance to help families plan for medical bills;
  - Pharmaceutical information for the medications that their loved one is taking, including education on any narcotic medications for safety;
  - Nutritional information for patients who may have different nutritional needs during treatment, including shopping and cooking resources;
  - Medical information to educate family members on their loved one’s condition and what they need to know concerning his or her treatment.
- Increase education and awareness of medical decision-making tools, including the availability of durable power-of-attorney laws in Michigan and streamline the creation of living wills, physician orders, or other documents.

Home Care:

- Involve state-level organizations to assist in the education efforts of providers and patients on palliative care and its role in the care of a serious illness.
- Develop a pilot program to improve reimbursement for palliative care in the home setting, possibly through the Health Innovation Fund.

Access to Needed Prescriptions:

- Create sensible, balanced regulations on access to opioids.
- Ensure that those who experience pain due to a serious illness, such as cancer, continue to have access to the pain medications their doctors prescribe.

Legislative Asks

- Create a Michigan Palliative Care Commission
- Appoint palliative care providers to Michigan’s Prescription Drug and Opioid Abuse Commission
- Develop a legislative task force to review health care decision-making tools and MI-POST laws
- Secure funding for palliative care provider training
- Update insurance code to provide coverage for palliative care teams
- Fund a pilot project for palliative care team reimbursement
Conclusion:

The landscape of palliative care is continuing to evolve in Michigan. Programs are either starting or growing in health systems around the state. However, there are still gaps in availability of this care. The goal of this report is to offer solutions for improving palliative care awareness and delivery statewide.
Acknowledgement:

Over the past year and a half many palliative care providers and policy makers have been involved with this process, we want to thank them for their time and knowledge.

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