



Palliative Care Advisory Council

LEGISLATIVE REPORT

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Palliative Care Advisory Council Legislative Report

Minnesota Department of Health
Comprehensive Cancer Control
PO Box 64882
St. Paul, MN 55164
651-201-5094
hilary.gebauer@state.mn.us
www.health.state.mn.us

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MDH Disclaimer

The Minnesota Department of Health is submitting this legislative report on behalf of the Palliative Care Advisory Council (the Council). The views and recommendations in this report are those of the Council and do not necessarily reflect the views and recommendations of the Minnesota Department of Health.

Executive Summary

The Minnesota Legislature established the Minnesota Palliative Care Advisory Council (the Council) in 2017 under Minnesota Statutes, section 144.059. The Council is charged with assessing, analyzing and making recommendations to the legislature on issues related to palliative care in Minnesota. The Council is required to report on its progress by February 15 of each year.

This report aims to:

- Provide information about the Palliative Care Advisory Council's efforts
- Provide information about palliative care
- Detail the Council's policy recommendations, which will become the foundation for its work in 2020

Palliative care, at its foundation, is about providing supportive care for patients living with one or more serious illnesses, and their families. Palliative care is intended to support the whole patient while they navigate the complexities of treatment and conversations with their medical team(s) and family members.

Recent studies highlight why supporting the whole patient and their family is important. Top barriers to goals of care discussions in a hospital setting center around the patient and/or their family members not understanding or agreeing with the patient's prognosis (You 2015). Another study found that health care agents make decisions for 50% of hospitalized older adults and up to 95% of patients in the intensive care unit (ICU). Decisions regarding medical treatments for the patient were based on the patient's well-being, not on the patient's preferences, 78% of the time (Devani 2017). Patient well-being is defined as what the family member or agent wanted for the patient. Patient preference is defined as what the patient has expressly requested either in conversations with their agent or documented in their advance care plan. The key to providing high quality serious illness care is aligning care with patient preferences.

Palliative care provides support to patients and families as they navigate difficult conversations and make tough decisions. This type of care helps patients and their families navigate today's complex medical landscape and eases suffering from pain and symptoms. Yet, according to data from the National Cancer Institute's Health Information National Trends Survey (HINTS 5, Cycle 2), 71% of US adults have never heard of palliative care (Trivedi et al 2019). Another study, using the same data, found that of the Americans who identified themselves as knowledgeable about palliative care, 60% held at least one misperception (Cheng et al 2019).

Increasing public awareness of palliative care will increase demand for palliative care services. To meet the need on a national level, the United States House of Representatives passed the Palliative Care and Hospice Education and Training Act (PCHETA), H.R. 647 October 2019. Testimony given in support of the bill highlighted the need to increase the supply of palliative care trained physicians. The current system produces approximately 350 new graduates annually (Dingfield 2019). Accounting for increases in the serious illness population, researchers estimate that the system needs to produce an additional 575 trainees per year (Kamal et al 2019).

Council members frequently hear stories about the challenges faced by patients and their families living with a serious illness. All too frequently patients or their loved ones say something along the lines of, "I wish I would have known at the beginning what I know today. I would have done things differently." Ensuring palliative care is provided early and frequently for patients and their families has been found to reduce patient regret and increase patient satisfaction (Donlon et al 2019).

In fact, palliative care best exemplifies the care needed to meet the principles of the Triple Aim and facilitate the move to the Quadruple Aim by improving clinician work satisfaction (Bodenheimer and Sinsky 2014). The “power of palliative care,” was praised in a recent report by New England Journal of Medicine Catalyst Insight Council. The Insight Council surveyed 572 health care executives, clinical leaders, and clinicians, and nearly all, 97%, agreed that palliative care and end-of-life care boosts patient experience and improves quality of care (94%). Eighty-eight percent of respondents reported that palliative and end-of-life care improves clinician work satisfaction and 79% agreed that palliative and end-of-life services lowers costs of care (Compton-Phillips and Seth Mohta 2019).

In order to focus efforts and prioritize areas of greatest need, data specific to Minnesota and a current assessment of the availability of- and barriers to receiving palliative care is needed.

In Minnesota’s current environment, palliative care is more likely to be seen as an ‘urban benefit’ in that the populations living near urban centers such as Minneapolis / St. Paul, Rochester, St. Cloud, and Duluth, and Moorhead are more likely to have access to home-based palliative care as well as palliative care within the clinic or hospital setting. Those populations living in rural or frontier locations are less likely to have access to either home-based or clinic based palliative care unless they drive into an urban center.

The Council is positioned to convene key stakeholders from across Minnesota to discuss the recommendations shared in this report in order to refine the recommendations of the Council; identify priorities within the recommendations; identify any gaps in the recommendations; and develop action steps for organizations to advance palliative care in Minnesota.

The remainder of this report provides a review of what palliative care is as well as the Palliative Care Advisory Council’s policy recommendations.

Summary of Palliative Care Policy Recommendations for 2020 and Beyond

The Council is putting forward 19 recommendations in 2020. A summary of the recommendations is outlined below. More detail regarding these recommendations is provided in later sections of the report.

1. Establish a clear definition for palliative care in state statute and relevant regulations, independent of hospice regulations.
2. Fund a statewide public education campaign around serious illness.
3. Fund a statewide public education campaign around end-of-life care.
4. Require a minimum number of hours of instruction in primary palliative care and pain management through state health professional licensure and continuing education guidelines for those who have Minnesota state licensure (Physician, Advanced Practice Provider, Registered Nurse).
5. Fund efforts to train professionals in primary palliative care.
6. Fund efforts to train professionals in specialty palliative care.
7. Support innovative certification opportunities for mid-career providers who want to focus in palliative care including tele-education and mentorship programs.
8. Establish or expand reimbursement programs for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Worker, Chaplain, Child Life Specialist).
9. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
10. Require medical schools to include minimum standards for primary palliative care education for all medical students.
11. Require physician residencies to include minimum standards for primary palliative care education for all residents.
12. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.
13. Ensure that palliative care benefits offered by private and public payers are comprehensive and support the full interdisciplinary team.
14. Expand access to home-based palliative care.
15. Expand access to pediatric palliative care in all settings to reduce the gap in services.
16. Establish a state-wide interdisciplinary palliative care research center or hub.
17. Require state regulatory agencies to develop measures, collect data, and report on palliative care access and quality. Measures should include disparities in access and utilization of palliative care across populations, care settings, and geography.
18. Encourage Minnesota based palliative care programs to participate in currently established national data collection efforts such as the Center to Advance Palliative Care National Palliative Care Registry.

19. Establish minimum standards for what constitutes a palliative care program with attention to challenges faced by different types of providers.

Minnesota Palliative Care Advisory Council: Background & Summary

The Minnesota Palliative Care Advisory Council (the Council) was established by the Minnesota Legislature in 2017 and will sunset in 2025. The Council is composed of 18 members representing a range of professional roles and personal experiences. Council members apply to serve on the council and are appointed by the Commissioner of Health. Council members serve in a voluntary capacity and receive no compensation or reimbursement.

The Legislature charged the Council with three tasks:

1. Assess the availability of palliative care across Minnesota
2. Analyze barriers to palliative care
3. Make recommendations to the Legislature

By February 15 of each year, the Council is required to report to the chairs and ranking minority members of the committees of the Senate and the House of Representatives with primary jurisdiction over health care.

While only required to meet two times per year, the Council has chosen to meet every other month. It has six active work groups that meet regularly and inform the bimonthly discussions and decisions of the full Council.

Work groups evolved out of a core framework the Council developed in 2018 at a strategy development retreat. During the retreat, the council identified six core focus areas and established six work groups for the duration of 2018-2019. The six work groups include:

1. Awareness
2. Education and Training
3. Policy
4. Reimbursement, Sustainability, and Delivery Models
5. Research, Data, and Metrics
6. Standards of Practice

Each work group is tasked with assessing barriers to palliative care and making recommendations that will advance palliative care across Minnesota. The Policy Work Group also monitors legislation that may impact/promote palliative care, provides legislative updates to the full council and supports the Council's efforts to review and respond to proposed laws, regulations, and policies. In 2019, the Council submitted a letter to lawmakers regarding legislation designed to address the opioid epidemic (Appendix A).

The Council is guided by the values of equity, autonomy, patient and family-centered care, and cultural sensitivity. The vision of the Council is that all Minnesotans have access to high quality palliative care across

populations, care settings, and geography. The Council agrees that “access for all” is the lens through which assessment work and recommendations are made. Expanding equitable and affordable access to palliative care, broadly defined, is the emphasis of the Council’s work.

Serious Illness

Introduction

Palliative care is appropriate for anyone diagnosed with a serious illness. Serious illness is, “a health condition that carries a high risk of mortality AND either negatively impacts a person’s daily function or quality of life, OR excessively strains their caregivers” (Kelley and Bolluns-Lund 2018). Examples of serious illness include cancer, heart disease, kidney disease, or dementia (CAPC 2019). Included in the definition of serious illness are acquired or genetic conditions such as brain injury, multiple sclerosis, Parkinson’s disease, amyotrophic lateral sclerosis (ALS), cystic fibrosis, Tay-Sach’s disease, muscular dystrophies, or spinal muscular atrophy.

The Commonwealth Foundation projects that approximately, “40 million adults in the United States are living with or have had a serious illness in the last three years” (Schneider et al 2018). An additional 400,000 children are currently living with a serious illness (CAPC 2019).

As our population ages, the serious illness burden will increase. By 2030, one out of every five Minnesotans will be 65 years of age or older. Among individuals 65 years and older, 81% live with multiple chronic conditions (Butteroff, Ruder, and Bauman 2017).

Challenges of Navigating a Serious Illness

Individuals living with serious illness face numerous challenges to their quality of life and experience significant losses. Serious illness can cause:

- physical pain and symptoms that make it difficult to enjoy activities
- emotional distress
- social isolation
- financial strain (Schneider et al 2018)

People with serious illness struggle to navigate a fragmented, complex health care system and are faced with difficult decisions about treatment, access to appropriate care, how to pay for care, and what matters most in life. Caregivers struggle to support their loved ones with limited resources, and physicians struggle under the weight of their workload (CAPC 2019).

Gaps in the serious illness care system result in failures to pursue advance care planning, costly interventions that often do not work, unresolved pain and suffering, unwanted hospitalizations, multiple trips to the emergency room, and a disconnect between patient preferences and the care they receive (CAPC 2019).

Serious Illness & Palliative Care

Palliative care can help ease the burden of serious illness for patients, their families, and the health care system. According to the CAPC, palliative care is, “specialized medical care for people living with a serious illness. Palliative care focuses on providing relief from the symptoms and stress of a serious illness. The goal is to “improve the quality of life for both the patient and the family” (CAPC 2019). It helps patients by controlling pain and symptoms, reducing stress and confusion among patients and caregivers, supporting shared decision-making and providing skilled communication.

Ideally, “palliative care is provided by a specially-trained team of doctors, nurses and other healthcare specialists who work together with a patient’s other doctors to provide an extra layer of support” (CAPC 2019). An interdisciplinary palliative care team usually consists of a physician, nurse, social worker, and chaplain – each of whom is trained in palliative care as a specialty. While such interdisciplinary teams are increasingly common in large hospitals in urban settings, individual healthcare professionals who are trained and licensed or certified often provide palliative care in other types of settings. “Palliative care is based on the needs of the patient, not on the patient’s prognosis. This care is appropriate at any age and at any stage of a serious illness, and it can be provided along with curative treatment.” Palliative care can be received in a variety of settings, including hospital, outpatient clinic, long-term care, freestanding hospice, or home settings (CAPC 2019). Some of these settings are referred to under the broader heading of “community-based palliative care”.

Palliative Care & Serious Illness: Care Cost Reduction

Palliative Care has been shown to achieve the triple aim of improving quality of care, improving patient outcomes, and lowering costs (Smith et al 2014). Studies have shown that palliative care reduces costs for high-need patients with serious illness. By reducing unwanted hospitalizations, emergency room visits, and providing treatments aligned with patients’ personal values and goals, the cost curve is positively impacted in patient-centered ways. One study found that palliative care consultations reduce hospital costs by \$3,000-\$4,800 dollars per admission; another, that savings of \$7,000 per patient were achieved by providing palliative care in the Medicaid population (May et al 2018; Morrison et al 2011).

Availability of Palliative Care

Hospital-Based Palliative Care

The Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC) collaborate to produce the *State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals*. The report tracks access to palliative care in hospital settings. The most recent edition of the report was released in 2019. Overall, access to hospital-based palliative care in the United States varies by region, facility size, facility type, and geography.

In Minnesota, 76% of hospitals provided palliative care in 2019 compared to 82% in 2015. All of Minnesota’s largest hospitals (defined as having more than 300 beds) provided palliative care in 2019 while only 39% of hospitals with fewer than 50 beds did. In 2015, 45% of small hospitals provided palliative care. CAPC’s National

Palliative Care Registry State Report uses 2015 data to analyze access to hospital-based palliative care by geography and reports that in Minnesota, access to palliative care is greater in urban areas than rural areas, with 79% of urban hospitals providing palliative care compared to 50% of rural hospitals. Updated geographic comparison data for Minnesota was not available at the time of this writing.

Community-Based Palliative Care

To expand access to palliative care beyond the hospital or hospice setting, more health care organizations are providing palliative care in the community. Examples of community-based palliative care settings include:

- office practices
- medical clinics
- long-term care facilities
- patients' homes (CAPC 2019)

Community-based palliative care allows patients and families to receive care in a more comfortable setting. Receiving care in the community improves patient and family quality of life and reduces exposure to costly and risky care provided in the emergency department and hospital.

Efforts to track access to community-based palliative care at the national level began in 2016 by CAPC. Through the *Mapping Community Palliative Care* project, CAPC developed a self-report survey of palliative care programs. At the national level, 890 community palliative care programs, serving 3,162 individual sites of care, were identified through the survey. The majority of community-based palliative care programs are run by hospitals or hospices. Seventy percent of community-based palliative care programs serve adults only.

In Minnesota, the *Mapping Community Palliative Care* project identified thirteen palliative care programs operated by nursing homes, seventeen programs offering services in the office or clinic setting, and nine programs operating in the home (GetPalliativeCare.org).

To address the rural access gap, Stratis Health has worked to expand access to rural community-based palliative care since 2007. Stratis Health has worked with over 23 rural Minnesota communities to explore, develop, or expand palliative care services. In their work, Stratis Health has learned that rural communities can provide effective palliative care services through innovation. There is variation in program structure across rural community-based palliative care programs. Rural communities need access to external resources, support, and learning networks to sustain their programs. The development of community-based metrics and broader reimbursement for services are also necessary for expansion and sustainability of services (Stratis Health 2016).

Palliative Care Workforce

Studies have indicated that the current palliative care workforce is not robust enough to keep up with increasing need for palliative care services. According to the American Board of Medical Specialties, there were 167 physicians certified in palliative care in Minnesota in 2017 and 169 in 2018, representing 0.01 percent of the total Minnesota physician workforce (ABMS 2019; 2018).

In nursing, Minnesota has 41 Advanced Certified Hospice and Palliative Nurses, 232 Certified Hospice and Palliative Nurses, 6 Certified Hospice and Palliative Pediatric Nurses, 1 Certified Hospice and Palliative Licensed Nurse, 27 Certified Hospice and Palliative Nursing Assistants, 5 Certified Hospice and Palliative Care Administrators, and 7 nurses Certified in Perinatal Loss Care (HPNA, 2018).

The number of other health professionals with certification and/or a specialty in palliative care currently practicing in Minnesota is unknown. Many professionals have specialized certification to provide palliative care through their profession and provide relief through palliative care support to patients and their caregivers. Even more provide palliative care but either do not have advanced certification or their profession does not yet provide it. This care has not been quantified.

Pediatric Palliative Care

In 2018, the Council conducted a pediatric palliative care assessment in partnership with the Minnesota Network of Hospice & Palliative Care (MNHPC), the Minnesota Cancer Alliance, and the University of Minnesota Community Health Initiative.

Forty-four provider members of the MNHPC responded to an online survey. Of the forty-four providers, only eight offer pediatric palliative care services. Geographic gaps were identified in northern Minnesota and parts of western and southern Minnesota (with the exception of Kittson, Wabasha, Dodge, Olmsted, and Fillmore counties).

The primary barrier to providing pediatric palliative care identified by providers was lack of education and trained staff. To increase access to pediatric palliative care, the report recommends various types of education be delivered in different modes based on each organization's needs. The assessment showed that training for pediatric palliative care is low, even in organizations that currently provide pediatric care, indicating an area for improvement. Future education should emphasize pediatric-focused staff training and should contain information on concurrent care to ensure patients are receiving proper coverage for both curative treatment and pain relief. The needs assessment identified that most providers prefer a combination of education (distance or local), 24-hour telephone support, and a state pediatric palliative care resource person.

Palliative Care at the End-of-Life

Palliative Care is an essential element in the continuum of care for any person of any age at any stage of a serious illness, regardless of their anticipated lifespan. Unfortunately, it is a common misconception that palliative care is *only* associated with end-of-life care or hospice. All hospice care by definition is palliative, but not all palliative care is end-of-life care. The equation of palliative care and hospice care has deterred many from requesting and receiving the full benefit of palliative care. The failure of health systems and facilities to develop adequate serious illness care models that include palliative care across the life span, or to have qualified palliative care staff, has meant that patients in some settings cannot access palliative care because they are not eligible for hospice or do not wish to enter hospice. Hospice is, "a special way of caring for people living with life-limiting illnesses" (MNHPC 2016). Patients with a diagnosed terminal illness and an anticipated 6 months or less of life are eligible for hospice care, which includes palliative care specifically for end-of-life needs.

Most hospice patients are eligible for the Medicare hospice benefit. Medicare data on hospice utilization gives us a sense of how many patients have access to palliative care at the end-of-life. Using Medicare data compiled by Hospice Analytics, MNHPC reports that 53% of Minnesota Medicare beneficiaries who died in 2017 were using hospice at the time of their death. The median amount of days spent in hospice was 27 days. Hospice utilization among minority populations was much lower at 38%. These findings suggest that many Medicare beneficiaries are not receiving palliative care at the end-of-life, those who are receiving palliative care at the end-of-life are receiving it for a limited time, and there is a 15% gap in utilization between white and non-white patients (MNHPC 2019).

Barriers to Palliative Care

Three primary barriers prevent palliative care from advancing in Minnesota:

1. Lack of awareness of palliative care by both the general public and healthcare professionals,
2. Lack of a trained workforce sufficient to respond to patient needs, and
3. Lack of a robust benefit set and reimbursement for palliative care services

These barriers can be addressed through public engagement, workforce development through professional education and licensure/certification, and expansion of palliative care benefits and reimbursement models.

Awareness

Recent national surveys suggest that public awareness of palliative care is low. According to data from the National Cancer Institute's Health Information National Trends Survey (HINTS 5, Cycle 2), 71% of US adults have never heard of palliative care (Trivedi et al 2019). Another study, using the same data, found that of the Americans who identified themselves as knowledgeable about palliative care, 60% held at least one misperception (Cheng et al 2019).

In 2011, MNHPC conducted a statewide survey of the serious illness needs of older Minnesotans, which is the most recent Minnesota specific data available. The survey found that 68% of 400 Minnesotans ages 50-80 had never heard of palliative care. Of the 32% who had heard of palliative care, most were unsure of what the term means (Cotroneo, 2011).

Sociodemographic trends shape awareness. According to Trivedi et al (2019), older adults, those with higher levels of education, women, and whites have greater odds of being familiar with palliative care. Other studies have looked at awareness of palliative care among caregivers. Awareness of palliative care among caregivers is higher than the general public, yet 55% of caregivers reported having "never heard" of palliative care. (Dionne-Odom et al 2019). Similar to other studies, many caregivers who are aware of palliative care held common misconceptions about it. Forty percent of caregivers who considered themselves familiar with palliative care reported that palliative care is the same as hospice, and associated palliative care with death (Dionne-Odom et al 2019).

CAPC commissioned a study to assess awareness and favorability of palliative care among the general public, patients, caregivers, and physicians. This study found that most Americans are generally unaware of palliative

care. However, they found that after being given the definition of palliative care, greater than 85% of consumers expressed favorable views and would be, “likely to consider palliative care for themselves or a loved one if they had a serious illness,” and over 90% believe palliative care services need to be available to patients and families (Harrington 2019).

Workforce

Another barrier to palliative care access is an insufficient trained palliative care workforce. As the population ages, the need for more palliative medicine specialists will grow. The current system produces approximately 350 hospice and palliative medicine specialists per year. To keep pace with anticipated need, it is estimated that the system needs to produce 500 to 600 specialists per year (Dingfield 2019).

There are also concerns about maintaining the current palliative care workforce. Researchers reported in Health Affairs that approximately 30% of the current workforce demonstrates burnout, 40% are approaching retirement age, and the demographic demand of palliative care-eligible patients will rapidly outpace the current supply of palliative trained physicians (Kamal et al 2019). Researchers calculated that there is currently one palliative physician for every 808 patients, and absent policy changes, by 2038 the ratio will be one palliative physician for every 1,380 patients (Kamal et al 2019).

Benefit Design and Reimbursement

The National Academy of Science, Engineering and Medicine stated in 2019, during the workshop, “Improving Access to and Equity of Care for People with Serious Illness,” that the key to improving serious illness care is to support a new payment and delivery model.

Historically, palliative care has primarily been available in the hospital. Recently, the demand for community-based palliative care has grown. However, payment for community-based palliative care remains a challenge.

Most people do not want to be in the hospital unless absolutely necessary. Professionals with palliative care skills can do many treatments and interventions at home. The current payment system is based on procedures and hospitalizations, and the fee-for-service model undermines attention to and reimbursement for pain and symptom management, shared decision-making and patient-provider communication. The payment and reimbursement model currently used is a barrier to providing palliative care for serious illness in the many settings where it is needed to support quality of life.

Palliative care in the community is not funded sufficiently to make it viable. However, some private payers are realizing the improved quality and cost savings of palliative care and are developing their own programs. Examples of private payers developing palliative care programs include Aetna’s Compassionate Care Program and Blue Shield of California (Baquiet-Simpson et al 2019).

Eight states, along with multiple payers, have taken the lead in developing policies and initiatives to improve access to home-based care for people with serious illness. This is a result of seeing the opportunity to provide better care, improve satisfaction and reduce costs. These states are Arizona, California, Florida, Iowa, Michigan,

New York, South Carolina and Washington. Across the nation payers include Aetna, Cambia-Regence, Blue Shield of California, Trinity Health System, OptumCare, and Sharp Healthcare (CAPC 2017).

Each state is unique in the way it provides the benefit, but they all:

- Include patient and family centered care
- Optimize quality of life by anticipating, preventing and alleviating suffering
- Serve patient and family needs through the continuum of the disease
- Address physical, intellectual, emotion, social and spiritual needs
- Facilitate patient autonomy, access to information and choice (Donlon et al 2019)

The efforts to promote palliative care provision includes services, support, education and collaboration. Savings gained from avoiding unnecessary emergency visits and frequent and/or prolonged hospitalization can cover the cost of these efforts. Development of policies to support reimbursement for palliative care is the right thing to do, not only for the seriously ill residents of Minnesota, but also for the health care system. More details on each state's benefits can be found on The National Academy for State Health Policy (NASHP) website, or individual state web sites.

If Minnesota follows their lead, it will be on the forefront of providing high quality care for its seriously ill residents. There are a few Minnesota based payers who are on the forefront and currently have a benefit for home-based palliative care services, but the offerings vary and are limited. Stratis Health, a Minnesota based non-profit and trusted expert in facilitating health care improvements, recently released the report, "Sustainability Strategies for Community-based Palliative Care: A Blue Print for Supporting Rural Palliative Care Services." This report highlights the need for the development of palliative care reimbursement model aligned across payers in the state.

Palliative Care Recommendations: 2020 and Beyond

Overview of Recommendations

The following section lists policy recommendations identified by the Council during 2019. Recommendations were developed through discussions, research, and stories experienced by and shared with Council members. The policy recommendations are grouped by the Council's work groups. These policy issues will constitute the framework for the Council's efforts during 2020, as it continues to address barriers to accessing palliative care in Minnesota. In addition, these policy recommendations will be shared with stakeholders and will be refined as the Council continues its work through 2025.

Awareness

As Council members navigate their own communities, they hear personal stories illustrating confusion and lack of awareness about palliative care on the part of patients, families, caregivers, and providers. There are stories of patients and families refusing palliative care, "because we aren't in hospice." There are stories of patient caregivers who have asked for and been refused palliative care support while navigating treatment for a loved one with multiple complex diagnoses, conflicting treatment goals, and challenging family dynamics. Increasing awareness of what palliative care is, and is not, is crucial in advancing palliative care in Minnesota.

Recommendations for Awareness

1. Establish a clear definition for palliative care in state statute and relevant regulations, independent of hospice regulations.

Rationale: Palliative care needs to be clearly defined to reduce or eliminate the misperception that palliative care is only provided at the end-of-life. Clearly defining palliative care in state statute and regulations will improve quality and consistency.

2. Fund a statewide public education campaign around serious illness.

Rationale: Current awareness of palliative care is low and misconceptions exist. Patients and families will benefit from increased awareness of the benefits of receiving palliative care at the time of diagnosis of a serious illness. Increased awareness among health care professionals will lead to more referrals and greater utilization of palliative care.

3. Fund a statewide public education campaign around end-of-life care.

Rationale: Hospice provides palliative care at the end-of-life. Palliative care provided through hospice can greatly ease the suffering of patients and families when a loved one is dying. The public needs to be educated about the benefits of palliative care at the end-of-life.

Education and Training

The Education and Training Work Group recognizes that creating a palliative care workforce is crucial for patient support as the population continues to age. As a result, this work group supports mandatory education early in the training of healthcare professionals in the definition, goals and value of palliative care in professional programs. Professional programs include medical schools, certain residency programs (family practice, internal medicine, general surgery, pediatrics, and other medical specialties), nursing, physician assistant, social work programs, and master's level chaplaincy. Education in bachelor's level programs should be focused to those roles that have potential for specialty level positions such as nursing and social work. This education should be mandatory to help spark the interest of pursuing careers in specialty practice.

In addition, education of primary palliative care knowledge and skills needs to be available and mandated for all healthcare workers, healthcare administrators and learners pursuing healthcare careers. The workgroup recommends the focus be two-fold – the current workforce and the future workforce. These two groups will need different education and training approaches going forward.

The work group recommends required continuing education each year dedicated to primary palliative care skills for the current workforce. This would be monitored through state licensing bodies. General information about palliative care, whole person pain management and communication skills would be good places to start for physicians, nurse practitioners and physician assistants. Consideration should also be given to adding education in palliative care skills to board and licensing requirements and testing for social workers, nurses and chaplains.

Policy recommendations (below) for palliative care education and training are grouped by recommendations for the current workforce, followed by recommendations for the future palliative care workforce.

Recommendations for Current Workforce

1. Require a minimum number of hours of instruction in primary palliative care and pain management through state health professional licensure and continuing education guidelines for those who have Minnesota state licensure (Physician, Advanced Practice Provider, Registered Nurse).

Rationale: Ensures all health care professionals achieve minimum palliative care knowledge and skills to retain licensing or certification.

2. Fund efforts to train professionals in primary palliative care.

Rationale: There is general agreement that primary palliative care skills are needed for anyone who works with people who have serious or potentially life-threatening illness. Those skills include basic pain and symptom management, initial goals of care discussions, shared decision making, understanding the ethical principles of care for the seriously ill, how to screen and attend to whole person needs, and basic understanding of end-of-life needs for patients, families, and caregivers.

3. Fund efforts to train professionals in specialty palliative care.

Rationale: Provide financial incentives for medical professionals to pursue advanced palliative care training. Specialty palliative care professionals achieve advanced level training and can address complex cases.

4. Support innovative certification opportunities for mid-career providers who want to focus in palliative care. Include tele-education and mentorship programs.

Rationale: Provide access to specialized palliative care education for non-traditional students whose existing work schedules conflict with time for traditional classroom settings.

Recommendations for Future Workforce

1. Establish or expand reimbursement programs for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).
2. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
3. Require medical schools to include minimum standards for primary palliative care education for all students.
4. Require physician residencies to include minimum standards for primary palliative care education for all residents.
5. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.

Rationale for Policy Recommendations 1-5 above: All educational programs should have agreed upon minimum standards to support high quality palliative care and ensure consistency in educational outcomes and continuity of core concepts across the disciplines related to palliative care.

Reimbursement, Sustainability, and Delivery Models

Across the country, recognition of the benefits of palliative care and the need for appropriate reimbursement is growing rapidly. Provision of palliative care aligns with the triple health care aims of, “improving the patient

experience of care (including quality and satisfaction), improving the health of populations, and reducing the per capita cost of health care.” Studies show home based palliative care improves satisfaction with care, reduces emergency department (ED) visits and hospitalizations, increases rate of in-home deaths, reduces 30-day readmissions, and reduces overall cost of care by 32-45% (Brumley et al 2007; Enguidanos et al 2012; Cherin et al 2004). A National Academy of Medicine report shows of the top 5% of health care utilizers, only 11% are in their last year of life and 40% of them will face multiple years of high utilization (CAPC 2017).

Palliative Care, like any program, can only be sustained by sufficient reimbursement. Palliative care is a good investment because it improves care and saves money.

Palliative Care has been proven to both improve care and reduce unnecessary cost (Smith et al 2014). Cassell et al (2016) showed how home- and clinic-based palliative care reduced hospital costs and total costs of care per month. Further detail shows it reduced number and length of hospitalizations, admissions in the final 30 days of life, use of the intensive care unit in the last 30 days of life and dying in the hospital. Taking into account the cost of the program, the return on investment for the palliative care program ranged from 4.2 to 6.6. Another study done by Morrison et al (2011), showed an average savings of \$7,000 per Medicaid patient in hospital. The NASHP has published a document titled “Palliative Care: A Primer for State Policymakers” and has a resource hub which can be accessed on their [website \(www.nashp.org\)](http://www.nashp.org). Home-based palliative care was shown to reduce cost by 36% which translates to \$12,000 cost reductions per patient (Lustbader et al 2017) by reducing care transitions from skilled nursing facility to ED or hospital by 43% (Miller et al 2016).

Palliative care is appropriate for anyone living with a serious illness regardless of age, stage of one’s illness, and setting, (e.g., inpatient, outpatient, clinic, hospital, hospice, or home). Reimbursement models must encompass and work for all provider arrangements, whether an urban palliative care provider with a full interdisciplinary team (IDT), or a single clinician in a Family Practice in rural Minnesota.

Recommendations for Reimbursement, Sustainability and Delivery Models

1. Ensure that palliative care benefits offered by private and public payers are comprehensive and support the full interdisciplinary team.

Rationale: In order for palliative care to be effective, the full team of physician, nurse, social worker, and spiritual counselor must be able to provide care. Reimbursement must be comprehensive to ensure that patients and families are receiving the full host of benefits offered by palliative care. Also, Minnesotans live in diverse environments from urban, rural, highly rural, and remote. Palliative care reimbursement models must support the ability of palliative care teams to operate in any of Minnesota’s diverse geographic settings.

2. Expand access to home-based palliative care.

Rationale: Patients using motorized scooters or children in strollers when they are not able to walk or navigate without them are currently disqualified from receiving palliative care benefits under the current system as they are not considered “home-bound.” Although able to leave their home, these patients are living with a serious illness and in need of palliative care coverage to maximize their quality of life (See Joe’s story in Appendix C).

3. Expand access to pediatric palliative care in all settings to reduce the gap in service.

Rationale: Pediatric patients who must go to an outpatient clinic to receive therapies or treatments when a home health provider is not available are no longer eligible for home palliative care. Families with children living

with serious illness face challenges on many fronts. The families are caring for the child with the illness and in many cases have other children in the family household. Palliative care provides support not only to the whole person, but also to the whole family as they navigate a complex and challenging medical environment.

Research, Data, and Metrics

Research is needed:

- to ensure palliative care is available whether the patient's location is rural or urban
- to determine the barriers to providing palliative care by measuring the availability of a trained palliative care workforce
- to determine patient barriers to receiving palliative care, e.g., disparities in access and utilization of palliative care across populations, care settings, and geography.

Recommendations for Research, Data and Metrics

1. Establish a state-wide interdisciplinary palliative care research center or hub.

Rationale: Research is needed to assess access to palliative care by location and setting across the life-span, advance clinical practice, develop interventions, evaluate palliative care programs, establish standards of practice or practice guidelines, and strengthen the operation of palliative care teams.

2. Require state regulatory agencies to develop measures, collect data, and report on palliative care access and quality. Measures should include disparities in access and utilization of palliative care across populations, care settings, and geography.

Rationale: Palliative care has the potential to address gaps in serious illness care. It is important to develop a standard set of measures so that providers and advocates are able to target their efforts to improve serious illness care. Efforts to measure the quality of serious illness care should pay special attention to disparities in access, utilization, and outcomes.

3. Encourage Minnesota based palliative care programs to participate in currently established national data collection efforts including the Center to Advance Palliative Care National Palliative Care Registry.

Rationale: These organizations have existing report cards that are published regularly. Currently, reporting is voluntary. These reports provide a cost-effective way of identifying some palliative care indices and facilitate an easy comparison to other states.

Standards of Practice

Standards of practice for palliative care are needed to ensure minimum standards are defined, understood and met to ensure quality care for the patient and their families. Standards can be divided into two areas; standards of care for delivery of care to the patient and standards of practice to establish programmatic delivery of such care. For the purposes of this report, we define standards of practice as the elements of a comprehensive interdisciplinary palliative care team and their most effective function in the healthcare system. Other forms of care might still be within the community standard from a more general perspective.

Recommendations for Standards of Practice

1. Establish minimum standards for what constitutes a palliative care program. Standards should include:
 - a. Interdisciplinary team
 - b. Assessment and management of symptoms
 - c. Advance care planning
 - d. Goals of care discussions
 - e. Care planning that is accessible to all team members and other treating entities
 - f. Provisions of care and support to family during illness and bereavement after death

Rationale: Minimum standards should be established with attention to challenges faced by different providers and should be informed by established guidelines published by the National Quality Forum (NQF), Center to Advance Palliative Care (CAPC), and Institute for Clinical Systems Improvement (ICSI).

Next Steps

The Council is positioned to convene interested organizations and individuals throughout the state for in-depth discussions of the Council's recommendations. The Council's goal is to ensure that its policy recommendations address and provide resolution for the unique challenges faced by patients and providers regardless of demographics or geographic locations and do not inadvertently create any unintended consequences, and truly result in palliative care "access for all."

The Council will continue to update its assessment of the availability of palliative care and barriers to palliative care. Through ongoing stakeholder engagement, the Council will refine its recommendations, identify priority areas, identify gaps in its recommendations, and develop action steps for organizations to advance palliative care in Minnesota.

Appendix A: Letter regarding legislation addressing the opioid epidemic

Dear Representative,

In 2017, the Legislature commissioned the Palliative Care Advisory Council ('PCAC') to assess the availability of palliative care in Minnesota, to analyze barriers to greater access to palliative care, and to create recommendations for legislative action. PCAC wishes to convey to the Legislature, in a timely way, considerations based on its study of the opioid problem in the context of palliative care and pain management.

PCAC supports legislation that addresses the opioid epidemic. However, any proposed legislation must avoid unintentionally harming individuals who require safe, appropriate and timely access to opioid medications for serious and life-threatening illness and otherwise unmanageable chronic pain. Appropriate pain and symptom management require the right evidence-based response, whether opioid or non-opioid, by providers trained in palliative care.

We urge legislators to

- Understand and reflect the differences among acute, chronic, and cancer pain management in opioid policy.
- Support continuing education for providers on palliative care pain management.
- Assure that palliative care patients with unmanaged pain, including pediatric patients with serious illness, have access to opioid medications as an essential component of quality palliative care.
- Consider exceptions to mandatory review for providers who are managing patients within palliative care and hospice settings, under the Prescription Drug Monitoring Program.
- Create effective drug take-back programs that provide cancer and other palliative and hospice patients with a safe way to dispose of unused medication.

Above all, PCAC recommends that lawmakers base pain management legislation efforts upon the latest research, best practices and expert input.

The Minnesota Palliative Care Advisory Council thanks you for your legislative efforts regarding effective legislation in the opioid and pain management area.

Sincerely,

Jessica Hausauer, Chair

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Virginia Thompson, R.Ph

Appendix B: Council Members

Council Members

Name	Seat	Term End Date
Tracey Armstrong	Care Coordinator	10/1/2020
Erin Balbach	Registered Nurse or Advance Practice Nurse	10/1/2022
Jody Chrastek	Registered Nurse or Advanced Practice Nurse (NBCHPN Certified)	10/1/2020
Karen Gervais	Member	10/1/2020
Audrey Hansen	Member	10/1/2022
Jessica Hausauer	Patient or Personal Caregiver, Chair	10/1/2020
Intisar Hussein	Licensed Social Worker	10/1/2022
C Scott Kammer	Health Plan Representative	10/1/2020
Deborah Laxson	Patient or Personal Caregiver, Vice-Chair	10/1/2022
Kirstin LeSage	Physician	10/1/2022
Elizabeth Mahan	Care Coordinator (Spiritual Counselor)	10/1/2022
Julie Mayers Benson	Physician (ABHPM Certified)	10/1/2020
Carol Shapiro	Patient or Personal Caregiver	10/1/2022
Dannell Shu	Patient or Personal Caregiver	10/1/2020
Adine Stokes	Licensed Health Professional	10/1/2022
Virginia Thompson	Licensed Health Professional	10/1/2020
Karen Wald	Licensed Health Professional	10/1/2022
VACANT	Physician Assistant (ABHPM Member)	10/1/2020

Membership of the Palliative Care Council must include:

1. Two physicians, of which one is certified by the American Board of Hospice and Palliative Medicine;
2. Two registered nurses or advanced practice registered nurses, of which one is certified by the National Board for Certification of Hospice and Palliative Nurses;
3. One care coordinator experienced in working with people with serious or chronic illness and their families;
4. One spiritual counselor experienced in working with people with serious or chronic illness and their families;
5. Three licensed health professionals, such as complementary and alternative health care practitioners, dietitians or nutritionists, pharmacists, or physical therapists, who are neither physicians nor nurses, but who have experience as members of a palliative care interdisciplinary team working with people with serious or chronic illness and their families;
6. One licensed social worker experienced in working with people with serious or chronic illness and their families;
7. Four patients or personal caregivers experienced with serious or chronic illness;

8. One representative of a health plan company;
 9. One physician assistant that is a member of the American Academy of Hospice and Palliative Medicine; and
 10. Two members from any of the categories described in 1-9 above.
- Council membership must include, where possible, representation that is racially, culturally, linguistically, geographically, and economically diverse.
 - The council must include at least six members who reside outside Anoka, Carver, Chisago, Dakota, Hennepin, Isanti, Mille Lacs, Ramsey, Scott, Sherburne, Sibley, Stearns, Washington, or Wright Counties.
 - To the extent possible, council membership must include persons who have experience in palliative care research, palliative care instruction in a medical or nursing school setting, palliative care services for veterans as a provider or recipient, or pediatric care.
 - Council membership must include health professionals who have palliative care work experience or expertise in palliative care delivery models in a variety of inpatient, outpatient, and community settings, including acute care, long-term care, or hospice, with a variety of populations, including pediatric, youth, and adult patients.

Appendix C: Glossary

Community-Based Palliative Care: Palliative care that is provided to patients in the community, separate from hospice services. Palliative care in the community is delivered outside of the hospital, either at home, in an office/clinic, or in a long-term care facility (CAPC 2019).

Hospice: Hospice care focuses on caring, not curing, and in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, nursing homes, and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, health maintenance organizations (HMOs), and other managed care organizations (NHPCO 2017).

Palliative Care (pronounced pal-lee-uh-tiv): Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve the quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and any stage of a serious illness, and it can be provided along with curative treatment (getpalliativecare.org).

Primary Palliative Care: Palliative care may be provided by clinicians who are not palliative care specialists. For example, internists, family medicine doctors, cardiologists, oncologists, and many other clinicians who care for seriously ill patients may provide basic palliative care. Palliative care provided by clinicians who are not palliative care specialists is sometimes called "primary" or "basic" palliative care (Schenker and Quill 2018). Representative skill sets for primary palliative care include: basic pain and symptom management, basic management of depression and anxiety, basic discussions about prognosis, goals of treatment, suffering, and code status (Quill and Abernathy 2013).

Serious Illness: Serious illness is a health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers (Kelley and Bollens-Lund 2018).

Specialty Palliative Care: Palliative care may be delivered by palliative care specialists who work alongside a patient's primary clinician. For example, a patient with advanced cancer may see a palliative care specialist in addition to his or her oncologist. This type of palliative care is called "subspecialty palliative care." Hospice and Palliative Medicine is now recognized as a medical subspecialty by the American Board of Medical Specialties, as well as in Canada, England, Ireland, Australia, and New Zealand (Schenker et2018). Representative skill sets for specialty palliative care include: management of refractory pain or other symptoms, management of more complex depression, anxiety, grief, and existential distress, assistance with conflict resolution regarding goals or methods of treatment within families, between staff and families, among treatment teams, assistance in addresses cases of near futility (Quill and Abernathy 2013).

Appendix D: Patient Stories - Why We Need Palliative Care

Joe

Joe is 80-year-old married man with Chronic Obstructive Pulmonary Disease (COPD). He cannot breathe well and needs oxygen all the time. He also has heart failure, arthritis and bowel and bladder issues. To receive home care he must be “home bound”, Joe enjoys going out on his “scooter” with his oxygen, unfortunately this disqualifies him for home care as he is not “home bound.” He has multiple symptoms- breathlessness, poor appetite and nutrition, constipation, and anxiety. His wife is showing signs of dementia. They are unable to afford private help and there is presently no funding to support in-home services which can help to prevent unnecessary hospitalizations. Their fall back is to go to the Emergency department at the local hospital.

Josie

Josie is 6 years old with a rare degenerative condition. Her parents are overwhelmed with her care which includes coordinating with multiple health care providers from different institutions, maintaining her regimen of medical feeding, bowels, pain, frequent pneumonias and hospitalizations. Josie’s siblings are acting out in school as they are not getting the needed attention. There is not a funded home-based service to help Josie and her parents manage her symptoms well at home and avoid unnecessary hospitalizations which they know are both emotionally and financially difficult.

Tom

Tom is a 67-year-old patient diagnosed with terminal cancer. Tom’s treatment included chemotherapy and a stem cell transplant to maximize the amount of time remaining in Tom’s life. However, the treatments and side-effects were so taxing on Tom, that he did not have enough strength to travel, play with the grandkids, or do the tinkering he loved to do. Thirty days before Tom died, he said he wished he would have just focused on pain management. He was miserable and the extended time he gained from the treatments was ultimately net zero since the quality of his life was so reduced.

Mabel

Mabel is an 85-year-old female with several chronic conditions, namely Chronic Obstructive Pulmonary Disease (COPD), congestive heart failure, high blood pressure, high cholesterol, and fatigue. Despite her conditions, Mabel is still living independently in the family home, still driving, volunteers at a local charity, and enjoys a weekly lunch with friends. Mabel has several children living within 15 minutes. Mabel was diagnosed with multiple myeloma, a terminal blood cancer. Mabel’s adult children, who are between 50 and 65 were divided on the treatment options proposed for treating the cancer. Several of the children believed Mabel should do the full chemotherapy protocols and “fight the good fight.” The middle daughter was the designated health care agent and had several private at length conversations where Mabel indicated she was tired and didn’t want to “fight.” She wanted to enjoy her remaining time. In order to please the family and despite her own reservations, she agreed to chemotherapy. The chemo left her sick and extremely fatigued and resulted in several hospital stays in the Critical Care Unit (CCU) where her health care decisions were now being made by

her designated health care agent. The health care agent had to ask the medical team several times for a palliative care consult as she needed more information and help in managing the expectations of her other siblings. The family finally received a palliative care consult where there was a lengthy discussion of the whole patient, the effects of the prescribed treatments and medications, and Mabel's goals and wishes for her care and remaining life. Ultimately the family agreed with managing Mabel's pain and taking only the medications that were treating her conditions prior to receiving the multiple myeloma diagnosis.

John

A success story.....

John was diagnosed with esophageal cancer several months ago and is undergoing second-line therapy. The pain is "terrible" and during another sleepless night, his overwhelmed and exhausted wife calls his doctor. She hears a taped voice telling her to hang up and call 911 if it is an emergency. This results in their fourth trip to the ED in 3 months.

After the last ED visit, John was admitted to the hospital for five days, followed by twenty-one days of post-acute rehabilitation, with little change to his treatment plan or his symptom burden.

On this fourth visit to the ED, his pain is an eight on a scale of zero to ten, for which he is taking a dangerously toxic dose of 5,000 mg of acetaminophen every day without relief.

At this point, the family is labeled a "frequent flier" and considered to be "abusing" the ED, despite their appropriate use of the only solution available to them.

A board-certified palliative medicine physician finally consulted with the couple on their fourth ED visit, and prescribed an effective pain management regimen that his wife could administer at home. This was the first time John's pain from the esophageal cancer was safely and effectively addressed. The family also received a series of home visits by a palliative care nurse and access to a 24/7 response line for any urgent issues. With these interventions, John avoided the ED and hospital for the next eighteen months, transitioning directly to home hospice care once his cancer progressed.

Citation: Stories based on CAPC 2017.

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