Minnesota Palliative Care Advisory Council

ANNUAL LEGISLATIVE REPORT

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Minnesota Palliative Care Advisory Council Annual Legislative Report

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Contents

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:

- Provides information about the Palliative Care Advisory Council's work in 2021.
- Provides information about palliative care.
- Details the Council's policy recommended actions, which will be the foundation for its work in 2022.

History will record 2021 as the year that began with the hope that the COVID-19 pandemic would be winding down or done by the end of the year. Vaccines had been approved for emergency use, vaccine production was in full swing, and vaccinations were being administered and managed through a controlled rollout to every corner of the state.

Confirmed cases, positivity rates, and hospitalizations began to decline mid-year. But, instead of a continual gradual decline indicating the worst was over, by fall Minnesota saw an alarming uptick in cases as the new COVID-19 Delta variant devastated the nation.

Instead of celebrating the end of the pandemic, Minnesotans continued to experience more sobering milestones. COVID-19 deaths surpassed 9,000 deaths on November 16th, ending the year at over 10,000 deaths.

As Minnesota experienced the COVID-19 surge in late 2021, many regions reported hospital and ICU bed availability down to 1% or 2% capacity. The health care system is strained due to how long some COVID-19 patients are staying in the Intensive Care Units (ICU). In some cases, patients are on a ventilator for two months or longer. Prior to COVID-19, having someone on the ventilator for a month would be tremendously rare.[1]

Some hospitals reported zero beds available and had to turn patients away.

Unfortunately, COVID-19 is leaving in its wake increasing numbers of patients with "Long COVID." Sometimes referred to as COVID "long haulers," these survivors are an entirely new group of seriously ill patients throughout Minnesota, whose enduring, possibly life-long, symptoms will continue to challenge health care providers, especially those with palliative care expertise.

In addition to the bed shortage, the statistics regarding health care workers was sobering. As the pandemic took its physical and emotional toll on health care workers, many left their employment, either by personal choice or by reduction in staff.

The Palliative Care Advisory Council (the Council) is a microcosm of the roles in healthcare. It consists of 18 volunteers. Fourteen of them are health care professionals. All members have experienced physical and emotional fatigue from the personal and professional turmoil created by COVID-19.

The Council, like so many other businesses and industries across the state, took a long hard look at members' capacity to commit their time to the Council's work. It became clear that capacity for volunteering was significantly reduced.

As a result, the Council reorganized from six workgroups into these three active workgroups:

- Education, Awareness, and Training
- Diversity, Equity, and Inclusion (formerly called Health Equity)
- Policy, Reimbursement, Sustainability, and Research.

The Education, Awareness, and Training workgroup focused its efforts this year on defining goals for increasing palliative care awareness and training for Minnesota's health care workforce.

The Diversity, Equity, and Inclusion (DEI) workgroup, originally called the Health Equity workgroup and created in 2020, renamed its workgroup to reflect the current challenges of diversity, equity, and inclusion in the current health care system. This workgroup informs the work of the Council by applying the Minnesota Department of Health's framework for assessing health equity impacts of health policies affecting Minnesotans.

The Policy, Reimbursement, Sustainability, and Research workgroup focused its efforts on what actions are needed to provide a solid foundation for the advancement of Palliative Care in Minnesota. The majority of this report focuses on the Palliative Care definition, what a defined set of core palliative care benefits might include, and an outline of a palliative care payment structure that could be tailored to align with the Council's proposed definition and set of palliative care benefits.

Many Council members attended Minnesota's Serious Illness Action Network summits in late 2021. During the August summit, the Council partnered with the Minnesota Network of Hospice and Palliative Care and Stratis Health to lead discussions about "Palliative Care Practice, Policy, and Payments". The November summit focused on caregiving and the burdens faced by family caregivers during their care recipient's disease trajectory.

Both summits were rich in detail and discussion. Information from local and national experts shaped the Council's considerations for a core set of palliative care benefits and payment models.

The Council learned that it typically takes about 20 years to progress from an idea, to policy, and ultimately to full implementation.[2] The Council heard from Torrie Fields, CEO of Votive Health, about Hawaii's 22-year palliative care journey, supporting the assertion of about 20 years from idea to actualization.

The Council recognizes it is time to start our own journey and shift from ideas and policy recommendations, to action, singling out critical next steps to advance palliative care in Minnesota.

After carefully evaluating all recommendations proposed this year and contained in prior annual reports, the Council puts forth the following four focused recommendations for action during 2022:

1. **Submit the Palliative Care Advisory Council's proposed definition of Palliative Care** to state legislators this session for action.
2. **Draft a recommended core set of palliative care services** for Minnesota.

3. **Collaborate with stakeholders**, such as the Department of Health and Human Services, **to identify and align palliative care payment models** to a recommended set of core palliative care services.
4. **Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures)** based on recommended palliative care payment models.

While all recommendations from prior years remain important, COVID-19 highlights the needs for a POLST registry and the need for more advance care planning for all persons over the age of 18 *(Recommendations 8, 10, and 13 from the Council's 2021 Annual Legislative Report. See Appendix B for a complete set of 2021 recommendations.).*

The Council recognizes it must create a solid foundation beginning with an agreed upon definition of palliative care in state statute. Building from the definition, the next step is to identify and recommend a defined set of core palliative care services, followed by development of payment models that align with the Council's proposed definition and defined services for palliative care in Minnesota.

The remainder of this report provides detailed explanations of the Council's recommended actions and their importance for the advancement of palliative care for all people in Minnesota.

The appendix includes the recommendations from 2020 and 2021 Palliative Care Advisory Council reports, along with reference materials that may be of interest to the reader.

The Council is committed to supporting diversity, equity, and inclusion. This report has been reviewed by the DEI workgroup using the DEI framework recommended by the Minnesota Department of Health.[3]

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[1] https://www.kare11.com/article/news/local/kare11-sunrise/st-cloud-hospital-federal-medical-teams-covid/89-94acfcc1-2f7c-4b8c-8fe7-125b4fe82a23

[2] Dr. Joe Gaugler, PhD, Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging, School of Public Health, UMN, Bridging the Family Care Gap, presented November 8, 2021

[3] https://www.health.state.mn.us/communities/practice/resources/equitylibrary/aecf-mission.html

The Definition of Palliative Care

Recommended Action #1. Submit the Palliative Care Advisory Council's proposed definition of Palliative Care *to state legislators this session for action.*

Minnesota's current definition of Palliative Care is found within Minnesota's Hospice Statute 144.75A which provides definitions and service requirements specific to **hospice**. As noted in the Council's 2021 report, including the Palliative Care definition within the hospice definition perpetuates the mistaken perception that hospice care and palliative care are interchangeable care models. They are not.

Palliative care can, and should, begin at the onset of a serious illness or condition, be provided along with curative treatments, and continue through the trajectory of the patient's disease or condition. Hospice care is for individuals anticipated to have six months or less to live and who are no longer receiving curative treatment.[1]

While palliative care is a key element of end of life, palliative care provides essential support appropriate at **any** age or stage of a serious illness or condition, often together with curative treatment.[2] Palliative care is appropriate to prescribe when a serious condition or illness is first identified, thus reducing the pain, symptoms, and stress of a serious illness or condition as early as possible.

Creating Palliative Care as a standalone definition in Minnesota statute allows the definition to be referenced appropriately by other regulations, such as regulations referencing opioids and pain management, or future regulations, where calling out palliative care would be appropriate.

The Council included a recommended definition of Palliative Care in the Council's 2021 report. Since that report, the Council sought feedback from the American Cancer Society Cancer Action Network and the Minnesota Alliance for Ethical Healthcare.

Based on their feedback, the Council modified the previously proposed definition to read as follows:

> *"Palliative care is specialized medical care for people living with a serious illness or life-limiting condition. This type of care is focused on reducing the pain, symptoms, and stress of a serious illness or condition. The goal is to improve quality of life for both the patient and family or care partner. It's a team-based approach, providing essential support at any age or stage of serious illness or condition, often together with curative treatment."*

Representative Liz Reyer will begin the legislative process for presentment of the Palliative Care definition during the next legislative session beginning January 2022.

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[1] https://www.cancer.org/treatment/end-of-life-care/hospice-care/what-is-hospice-care.html

[2] https://www.capc.org/about/palliative-care/

Defining a Set of Palliative Care Services

***Recommended Action #2: Draft a recommended core set of palliative care services** for Minnesota.*

With the definition of Palliative Care established in the previous section, the **Council will focus efforts during 2022 on recommending a core set of palliative care services** for Minnesota.

As noted during the November Serious Illness Action Network summit focused on family caregiving, it is important for medicine to evolve from person-centered to family-centered care when the patient is first diagnosed with a serious illness or condition.[1] Palliative care is well-positioned to help providers, patients, their families, and caregivers make that transition.

An infographic published by AARP in November 2019 indicates that family caregivers are carrying out increasingly complex tasks, like wound care and giving injections. There are currently 7.1 potential family caregivers for every person 80+ years of age. This ratio is projected to shrink to 4.1 to 1 by 2030. The aging of the population and its impact on families can no longer be viewed as a private, family-only issue,[2] making families and caregivers a valuable part of the palliative care interdisciplinary team, or IDT.

As noted in the recommended definition of palliative care, the goal of palliative care is to improve quality of life for both the patient and their family or care partner.

The remainder of this section introduces elements under consideration for inclusion in a core set of palliative care services.

Considerations include:

- Patient eligibility
- Medical needs of the patient and supportive needs of the patient and family or care partner
- Composition of the interdisciplinary team, and the medical and supportive services they provide for the patient and family/care partner

According to the National Consensus Project for Quality Palliative Care Clinical Practice Guidelines, patients **that should be considered eligible for palliative care include:**[3]

- Individuals living with chronic life-threatening injuries from accidents or other forms of trauma
- Neonates, children, adolescents, and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care, supported by others to perform their activities of daily living
- Neonates, children, adolescents, and adults with developmental and intellectual disabilities who develop serious or life-threatening illness
- Individuals, of any age, with acute, serious, and life-threatening illness (e.g., severe trauma, acute stroke, and leukemia), where cure or reversibility is a realistic goal, but the conditions themselves and/or their treatments pose significant burdens and result in poor quality of life
- People living with progressive chronic conditions (e.g., peripheral vascular disease, malignancies, renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders, and the various forms of dementia)

- Seriously ill and terminally ill patients (e.g., people living with end-stage dementia, terminal cancer, or severe disabling stroke) who are unlikely to recover or stabilize and for whom intensive palliative care is the predominant focus and goal of care for the remainder of their lives

It is important to remember that palliative care can be, and should be, a benefit provided to all patients in any of the above eligibility categories regardless of care setting, employment status, or lack of financial resources. Care settings, in addition to hospitals, veterans' hospitals, and community clinics, may also include private residences, assisted living facilities, rehabilitation centers, skilled and intermediate care facilities, acute and long-term care hospitals, clinics, hospice residences, correctional facilities, and homeless shelters.[4]

Medical needs considered could include:

- The complexity of care currently received by the patient, (e.g., the number and frequency of visits with the patient's doctor(s) or specialist(s) requiring the need to coordinate with multiple providers)
- Pain and symptom management
- Referrals to other doctors
- Continuity of care between care locations, (e.g., home to hospital, hospital to long term care facility, hospital to home, to veterans' homes, homeless shelter, correctional facilities)

Supportive needs of the patient and family or care partner could include:

- Support in advance care planning and difficult health care decisions so treatment goals align with patient's goals of care
- Support in documenting health care decisions (advance care planning, POLST).
- Support during difficult family conversations
- Help in navigating the health care system
- Spiritual, emotional, and physical support
- Patient and caregiver education about the patient's specific medical illness or condition.
- Anticipatory grief and bereavement support
- Caregiver support
- Find connections for resources to help improve quality of life

An **interdisciplinary team** (IDT) team addresses the **patient's medical needs** and the **patient/ family/ care partner supportive needs.**

A **core IDT** consists of:

- Physicians, Physician Assistants, or Advanced Practice Registered Nurses (APRN)
- Nurses
- Social workers
- Spiritual counselors
- Family members or care partner

Additional members who could be added to the IDT based on the complexity of the patient's medical or patient's/family's/care partner's supportive needs include:

- Dietitians
- Therapists
- Pharmacists
- Integrative health providers trained or certified in:[5]

  - Acupuncture
  - Acupressure
  - Aromatherapy
  - Music therapy
  - Massage therapy
  - Healing Touch

Merging the complexity of the patient's serious illness or condition, the medical needs, with the supportive needs of the patient and their family or care partner suggests the utility of a tiered set of palliative care services.

Palliative care services could be defined by creating a defined set of core services, for example Tier 1, Tier 2, and Tier 3 (see below). For this illustration, Tier 3 is the lowest level, with additional support layered on as the patient's medical care needs and supportive care needs require a higher tier of care moving them to a Tier 2 or Tier 1.

For illustration only, consider how a tiered defined set of palliative care benefits might look when the patient's medical care needs and the patient/family/care partner supportive care needs are both considered:

- **Tier 1 [high level of support]:**
  - Patient requires high medical care and patient/family/care partner has high supportive care needs
  - Patient requires moderate medical care, and the patient/ family/ care partner has high supportive care needs
- **Tier 2 [moderate level of support]:**
  - Patient requires moderate medical care, and patient/family/care partner has moderate supportive care needs
  - Patient requires low medical care, and the patient/family/care partner has moderate supportive needs
- **Tier 3 [lowest level of support]:**
  - Patient requires low medical care, and the patient/family/care partner has low supportive care needs

The goal is to provide standardized palliative care consistently throughout life and across care settings (including inpatient, outpatient, community, and long-term care), from the earliest moment after diagnosis to end-of-life, and through the bereavement period of the family and caregivers.

It is the goal of the Council to recommend, consistent with the definition it has proposed to the Legislature, a defined set of palliative care services by the end of 2022, laying the foundation for the development of a consistent, standardized payment model for palliative care.

A palliative care payment model is discussed in the next section.

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[1] Dr. Joe Gaugler, PhD, Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging, School of Public Health, UMN, Bridging the Family Care Gap, presented November 8, 2021

[2] https://press.aarp.org/2019-11-14-Valuing-the-Invaluable-Series

[3] Clinical Practice Guidelines for Quality Palliative Care, Third Edition, National Consensus Project for Quality Palliative Care, page 8

[4] Clinical Practice Guidelines for Quality Palliative Care, 4th Edition, National Coalition for Hospice and Palliative Care, page 5

[5] See Minnesota Revisor for a list of complementary or alternative health care practices. Sec. 146A.01 MN Statutes

Palliative Care Payments/Reimbursement

***Recommended Action #3: Collaborate with stakeholders**, such as the Department of Human Services (DHS), **to identify and align palliative care payment models** to a recommended set of core palliative care services.*

This report recognizes the nuance between **payment** – service provided, and payment made at the time the service was received, typically made by the patient – and **reimbursement** – when the service is billed after the service is received, typically submitted to a third-party payor, creating a lag between the time of the service and when the bill is considered paid. In health insurance, third party payors are either public, e.g., Medicare, Medicaid, or private, e.g., commercial health insurance companies.

For consistency this report uses the term **payment** which is intended to include both **patient payments and reimbursements** from third party payors for medical care received.

The Council had the opportunity to attend the Serious Illness Action Network August 2021 Summit focused on "Palliative Care, Practice, Policy, and Payments." Speakers at the event were recognized local and national leaders in palliative care.

While palliative care is the right thing to do, providers are challenged with inconsistencies between the palliative care benefits and payments allowed by individual payors. Providing palliative care in rural communities is even more difficult when providers may only have two or three patients per payor leading some providers to consider not billing due to administrative hurdles.[1]

Since 2015, the Center to Advance Palliative Care (CAPC) has been collecting ideas and approaches from diverse payors including Medicare Advantage Plans, Medicaid Managed Care, commercial insurers, integrated payor-providers, and full risk providers. Their learnings support the need to identify the payment model that best supports the services needed by each population.[2]

CAPC's recommends that payment models be variable. Using a gas burner as an illustration, payments should be able to 'dial up' for higher intensity care resulting in higher payments, and 'dial down' for lower intensity care resulting in lower payments. The goal for payments is to strive for consistency across payors.[3]

Again, for illustration only, the tiered set of palliative care benefits suggested in the previous section creates the foundation for a variable payment model as CAPC suggests.

The task then becomes aligning existing payment models with the tiered approach for services. In some cases, a tier may require two or more payment models to be applied.[3]

Common payment models, as identified by Allison Silvers of CAPC, include:

- **Fee-for-service**, typically used for assessment and consultation
- **Episodic payments**, typically for 30-, 45- or 60-day periods; recertify if additional services needed
- Monthly bundled, **per** member **per month,** is a 'go to' payment model for many payers
- **Tiered bundled**, may become the next popular option. High, medium, and low depending on patient needs
- **Financial incentives** for inpatient palliative care

  Note: Financial incentives in general seek to influence provider behaviors whether clinician, hospital, specialty care, or palliative care. Incentives should be based on quality measures including access to care, patient satisfaction, advance care planning, clinical quality.

The goal of the Council for 2022 is to align palliative care payments with services, again aiming for consistency regardless of patient, place [care setting], provider, or payor.

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[1] Stratis Health Research Sustainability for Community Based Palliative Care, Karla Weng, August 2021 presentation

[2] Center to Advance Palliative Care, Allison Silvers, August 2021 presentation

[3] Ibid.

Palliative Care Comparative Cost Study

Recommended Action #4: Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) *based on recommended palliative care payment models.*

The Center to Advance Palliative Care (CAPC) states that palliative care focuses on the highest-need, highest-cost patients.

> *"High spending in health care is not limited to those at the end of life. Palliative care is for all individuals with serious illness who face heightened risks of crisis hospitalization and preventable spending – often over years. Of the top 5% of health care utilizers in the United States, only 11% are in their last year of life, with a full 40% facing year after year of high utilization."*[1]

Looking at the costliest 5% of health spenders CAPC noted the following:

- 11% were in the last 12 months of life
- 49% experienced a short-term high spend
- 40% had a persistent high spend over years

Palliative care improves quality of life and reduces symptom burden. Palliative care provides the care that patients want – and *because it meets their needs*, it reduces unnecessary utilization of crisis care. Its focus on the highest-need and highest-cost patient segment, accounting for the majority of spending, makes it an essential strategy for population health management.[2]

The Council recognizes there is very little Minnesota specific payment studies available. The Council also recognizes that a comparative cost study should be conducted on Minnesota patients, using Minnesota's criteria for palliative care eligibility and potential payment models.

At the state level, Minnesota controls services offered through Minnesota Assistance [Medicaid], Minnesota Care [low-income], and the State's Employee Health Plan. These three populations provide the most appropriate place to start a state level comparative cost study on the costs and savings associated with existing palliative care offerings in the state.

The Council requests that the appropriate state agency or agencies conduct an 'on paper' comparative cost study based on one or more of these populations, similar to the study noted in an article published by the Journal of American Medical Association (JAMA). This study contrasted patients who received palliative care with patients with a similar health condition who had not received palliative care and found:

- Patients who **received palliative care** consultation and **were discharged alive** [experienced] significantly lower costs than usual care patients **including savings** of:
  - $2,642 per admission / $279 per day
  - $1,696 per admission / $174 per day in direct costs associated with palliative care
  - $424 per admission in laboratory costs
  - $5,178 per ICU admission
- Patients who **received palliative care** consultation and **died in the hospital** [experienced] significantly lower costs than usual care patients **including savings** of:

- $6,896 per admission / $549 per day
- $4,908 per admission / $374 per day in direct costs associated with palliative care
- $1,544 pharmacy costs per admission
- $926 laboratory tests per admission
- $6,613 per ICU admission. [3]

The purpose of a Minnesota specific comparative cost study is intended to determine if our palliative care program will produce similar results to the results identified by CAPC and JAMA.

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[1] The Case for Community-Based Palliative Care | Center to Advance Palliative Care (capc.org)
[2] Ibid.
[3] https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/414449

Education, Awareness, and Training Workgroup

The Education and Training Committee has set the following goals for 2022:

- To increase palliative care awareness and training of the ***current*** health care workforce:
    - All physicians/APCs/providers who work with patients with serious illness (hospitals, long term care centers, assisted living facilities, outpatient clinics (both primary care and specialty clinics such as nephrology, neurology, cardiology, pulmonology, rheumatology, oncology, pediatrics…)
    - Social workers, chaplains and RNs who work with patients with serious illness in all settings as noted above
    - Focus on training would include but not limited to
        - Primary palliative care skills such as symptom management, serious illness conversations, how to break bad news, use of POLST
        - Increased familiarity of specialty palliative care roles and when to refer
        - Increased familiarity of hospice qualifications and when to refer (to avoid crisis and late referrals)

- To increase palliative care awareness and training of ***new learners*** as identified as those still in training (medical school, graduate school, nursing school, etc.):
    - Require nursing schools to include minimum standards for primary palliative care education for all nurses
    - Require medical schools to include minimum standards for primary palliative care education for all students. Training topics could include communication, physical and non-physical pain and symptom management in serious illness, shared decision making, and understanding of the structure and continuum of palliative care
    - Require physician residencies to include minimum standards for primary palliative care education for all residents
    - Include and mandate more advanced palliative care education and skills in key physician fellowships including oncology, radiation oncology, cardiology, geriatrics, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery

With these goals in mind the committee has explored several options for implementation and continues to pursue best practices in these areas including:

Options for current workforce:

State level - require a minimum number of hours of instruction in primary palliative care and/or pain management through state health professional licensure and continuing education guidelines, for all core palliative care team member roles (MD/DO, NP, RN, SW)

Pros

- Single point of data collection at the licensing board level
- Likely to reach target audience as all need to renew licensure annually
- Could potentially house resources and training options on the board website

- High quality online/virtual trainings already exist and so do not need to be developed though may need some adaptation

Cons

- Mandating continuing education has not been shown to be effective; there is no evidence to support this format of learning
  - On the job training or just in time training is more effective for the learner but much harder to monitor
- The time required to adequately train current workforce is likely greater than their capacity and/or desire to consume it

Employer level - require a minimum number of hours of instruction in primary palliative care and/or pain management (needs further exploration)

Pros

- Precedent for this type of education already exists for health systems/hospitals for privileging
  - ACLS, ATLS, BLS, ALSO, PALS, NRP…
- This would target providers, RNs, social workers, chaplains
- Module type classes already exist for some disciplines and are ideal for virtual or on demand learning (ELNEC)
- Easy to monitor through a credentialling department
- Could follow a provider wherever they practice in Minnesota

Cons

- Cost – employer vs employee?
- How often would an eligible employees need recertification
- Capacity for many required trainings may be taxing to certain disciplines

Payor level - require a minimum number of hours of instruction in primary palliative care and/or pain management (needs further exploration)

Pros

- This would target providers who are required to be credentialed by payers
- Could follow a provider wherever they practice in Minnesota
- Generally credentialing departments would help gather the appropriate data and proof of training

Cons

- This would miss other disciplines such as social workers, chaplains, nurses
- Different payors could have different requirements which could cause confusion, frustration and ambivalence
- Cost – who would cover?

Minnesota Department of Health level - require a specific metric around palliative care education

Options

- Build metric around provider documenting specific serious illness conversations in the EMR (this would imply awareness, though not skill level)
- Build metric around documentation of completion of POLST for appropriate patient HCC codes

Pros

- This would target providers (a key target)
- This would be easy to monitor once built into EMRs
- Could give live feedback to providers and could flag providers to meet this metric using appropriately built systems in EMRs

Cons

- As one of many metric options available on the slate not all organizations would necessarily choose to monitor this metric
- Building software code around metric for EMRs will have a cost (who funds?)
- Only targets providers, not necessarily social workers, chaplains, and nurses though they all could be part of the documentation

Minnesota Hospital Association level

– contract with MHA to develop quality improvement projects for all hospitals and health systems around palliative care training and awareness

Pros

- Precedent for this type of education already exists for health systems/hospitals
  - MHA has a long history of high-quality projects around other serious illness topics like delirium, sepsis, pressure ulcers and patient and family engagement
- Projects like this engage not only all the pertinent players – providers, social workers, chaplains, nurse but also hospital and health system quality improvement specialists, managers, and administrators.

Cons

- Not all hospitals and therefore not all targeted disciplines are members of MHA

Take-away points for these forms of required training

- If pursued then target the audience carefully, do not cast a wide net
- Before implementation determine who and how monitoring will occur and be documented
- Regulate in statue as opposed to licensing boards as they may not be equipped to manage this (ie opioid education requirements)
- Ideal format is short (1-4 hours), free to learner, online/on-demand and standardized
- Ideally this would be over a specific timeline (e.g., 2-4 years)
- Need to consider how to handle those who do not follow through with the requirements (what are the consequences)
- The current healthcare crisis around COVID is a pain point that needs to be utilized
- Partner with known organizations that are already providing this education, e.g., PCNOW, Ariadne Labs, Respecting Choices, Vital Talk
- PCHETA – Palliative Care and Hospice Education and Training Act is likely to pass at the federal level in the next few years. Minnesota is a leader in palliative care and should prepare to apply to be a funded site of education

Diversity, Equity, and Inclusion Workgroup

Today it is not difficult to look beyond the boundaries of our community to see that we have faced a tipping point in the delivery of health care and palliative care, exacerbated by COVID-19. We have a deeper understanding of how certain communities are disproportionately impacted by this pandemic and this further highlights the gaps in care and access to care in our community. It is no longer acceptable as a state to support delivery of healthcare without also swiftly assessing and making direct improvements to healthcare for all people in Minnesota. The time for impactful change is now.

> *Events of the past year, including the disproportionate impact of COVID-19 on racial and ethnic communities, placed an overdue spotlight on issues of racial inequity. This prompted health care institutions to examine both their internal approaches to diversity, equity, and inclusion (DEI), and disparities in health care access and quality for patients. As a result, many palliative care leaders acknowledged their programs fell short and began to tackle the challenge of advancing equity initiatives in the design of their palliative care services.*
>
> -Center to Advance Palliative Care. June 2021

Over the past 18 months, national and international organizations and leaders (e.g. American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, National Institute of Health, and including the United Nations Human Rights Office of the High Commissioner, among countless others) have released statements of support and ideas for the direction of change. However, more importantly has been the timely development of tools which provide direction for rigorous analysis and identify a path for understanding, change and improvement. These steps are necessary to pave the way toward systemic change in healthcare, specifically palliative care - starting from assessment to implementation.

An article in The New England Journal of Medicine[1] by Michelle Morse, MD, MPH, and Joseph Loscalzo, MD, PhD, experts in the field of transformational medicine, appropriately describes the challenges we face and the work that needs to be done:

> *"In fact, our clinical training has the potential to create a mindset that directly conflicts with the visions espoused by social movements. Clinical training creates a mindset of urgency; a focus on short-term goals and on fixing and curing; an expert identity, sometimes with distaste for being challenged; and risk aversion. These attributes are, for the most part, necessary and desirable in clinicians, but they can be counterproductive in the context of social movements. The social transformation that movements seek requires long-term vision, building power for enacting change over time rather than implementing rapid solutions, humility, a willingness to take chances despite uncertainty, and a learning mindset."*

And, more importantly those who do not access health care – either because of income, insurance, access to preventive care or ongoing care, or fear and mistrust of receiving treatment. Treatment of pain in Black patients is a perfect example of how this intersects with palliative care, opioid use, and even access to palliative services when pain is not assessed the same for a Black patient (foundational study from 2016):

As noted in an article published by the US National Library of Medicine, National Institutes of Health, racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between Blacks and whites[2] results in Black Americans being undertreated for pain relative to white Americans.

> *"The present work examines beliefs associated with racial bias in pain management, a critical health care domain with well-documented racial disparities. Specifically, this work reveals that a substantial number of white laypeople and medical students and residents hold false beliefs about biological differences between blacks and whites and demonstrates that these beliefs predict racial bias in pain perception and treatment recommendation accuracy. It also provides the first evidence that racial bias in pain perception is associated with racial bias in pain treatment recommendations. Taken together, this work provides evidence that false beliefs about biological differences between blacks and whites continue to shape the way we perceive and treat black people—they are associated with racial disparities in pain assessment and treatment recommendations."*

During 2021, the Diversity Equity and Inclusion (DEI) working group has reviewed the recommended strategies from organizational leaders, beginning to identify recommendations and even reviewing DEI toolkits that have been developed in the past five years to identify ways to make improvements and changes in healthcare delivery. Over the next 12-24 months a deeper assessment will be performed within the working group to compile a reference list of recommended resources which can be included for future reports.

Additionally, the workgroup will continue to integrate opportunities for inclusion of DEI concepts and ideas and discussion within regular meetings. Also important in 2022 will be the development of a plan to engage and elicit feedback from a diverse group of community members, especially those who have been disproportionately impacted by COVID-19 (e.g., BIPoC, LGBTQ+, etc.).

In 2021, the DEI working group has recommended using a tool developed by the Minnesota Department of Health: Health Resources and Services Administration Equity Tool, "Advancing health equity: Key questions for assessing policy, processes, and assumptions (state.mn.us)" to analyze and assess the 2021 PCAC report and recommendations for policy and statute. This is one small step that will assist the council in improving and advancing our report to ensure that the needs of those living in Minnesota are represented.

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[1] https://www.nejm.org/doi/full/10.1056/NEJMp2002502

[2] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4843483/

Next Steps

As 2021 ends, the Council recognizes our major achievement this year has been advancing the definition of palliative care in Minnesota to lawmakers thus beginning the process of transforming language into statute.

As the Council reflects on its responsibilities, an assessment of palliative care in Minnesota, an analysis of barriers to greater access to palliative care, and recommendations for legislative action, with draft legislation to implement the recommendations, the Council recognizes the most significant barrier to expanding palliative care in Minnesota is simply put, the complexity and inconsistency of payments across care settings and payors.

While prior annual legislative reports focused on identifying recommendations, this report shifts from just recommendations to recommended actions to advance palliative care.

These four actions, shown below, while simple, will not be easy to accomplish without strong partnerships across public and private sectors.

RECOMMENDED ACTIONS:

1. Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators this session for action.
2. Draft a recommended core set of palliative care services for Minnesota.
3. Collaborate with stakeholders, such as the Department of Health Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
4. Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.

Completing Actions 1-3 will provide a solid foundation for palliative care in Minnesota, from educational materials for both the public and providers, to training, licensure, and ultimately consistency in payments.

The Council is grateful again this year for the continued support, collaboration, and partnerships with the Center to Advance Palliative Care, the Serious Illness Action Network, the Minnesota Network of Hospice and Palliative Care (MNHPC), Stratis Health and the Minnesota Alliance for Ethical Healthcare, and the American Cancer Society Cancer Action Network.

The Council looks forward to the next steps on the journey toward providing quality palliative care with access to all Minnesotans.

Appendix

Appendix A: Summary of 2022 Key Recommended Actions

1. Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators this session for action.
2. Draft a recommended core set of palliative care services for Minnesota.
3. Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
4. Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.

Appendix B: Summary of 2021 Key Recommendations

This summary does not include all the identified recommendations but rather identifies the few key recommendations for 2021 as follows:

1. Consider revising the language in 144.75A Subdivision 12 to eliminate the exclusive association of palliative care with hospice care.
2. Adopt the suggested definition of Palliative Care for Minnesota. *(See* Definition *Section for suggested language.)*
3. Enable Minnesota's Medical Assistance and MinnesotaCare to pay for high-value services such as palliative care and advance care planning to benefit those with serious illnesses or life-limiting conditions using existing CPT or HCPCS codes.
4. Explicitly incorporate palliative care into existing Medical Assistance and MinnesotaCare waiver programs that focus on high need patients.
5. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the "loaded miles" benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
6. Consider making palliative care coverage a requirement for all Medical Assistance and MinnesotaCare managed care contracts in the next contracting cycle.
7. Consider adding palliative care coverage requirements in all settings to Medical Assistance and MinnesotaCare managed care organization contracts, including special considerations for pediatrics, adolescent, and young adult, and perinatal.
8. Rethink how technology can support those with serious illness care.
9. Develop a registry for physician orders for life-sustaining treatment (POLST) and advance care planning (ACP) documentation.
10. Improve access to and support for the use of technology for patients and caregivers.
11. Normalize and proactively support ACP as part of health care delivery.
12. Support workforce development and confidence in technology use for remote care delivery.
13. Reduce variations in coverage and payment requirements across payers that make it challenging to develop and deliver serious illness care.
14. Provide adequate reimbursement and regulatory incentives for increasing utilization of ACP.
15. Implement regulatory and reimbursement flexibilities to structure services that better meet the needs of seriously ill patients.
16. Improve access to and consumer experience for all needed care service – primary, specialty care, and hospital care. (see the Health Equity Section for a list.)
17. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the "loaded miles" benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
18. Request research on rural transportation challenges affecting access to timely, appropriate health care (including palliative care).

Appendix C: Summary of 2020 Key Recommendations

During 2019, the Palliative Care Advisory Council identified the following 19 recommendations to improve and strengthen palliative care within Minnesota.

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.

Appendix D: Summary Serious Illness Action Network August 2021 Summit on Palliative Care: Policy, Practice, and Payments

Minnesota's Serious Illness Action Network (SIAN) held their second summit August 13, 2021, focused on Palliative Care Practice, Policy, and Payment.

Participants, including Council members, heard presentations from state and national palliative care payment experts, including Minnesota's own Karla Weng with Stratis Health, along with Allison Silvers, Vice President Center to Advance Palliative Care (CPAC), and Torrie Fields, CEO Votive Health (Hawaii).

What we learned from Stratis Health Research Sustainability for Community Based Palliative Care (Karla Weng)

During late 2018, Stratis Health, as part of a continuing effort to help rural programs expand palliative care services, held roundtable discussions within existing programs in Minnesota and surrounding states.

Their findings highlighted how critical palliative care payments are for rural providers. **Current payment models** for use by rural providers include:

- Billing and traditional reimbursement
- Grants and philanthropy
- Value-based contracting

Note: Grant funding is typically awarded to start a program, is not the same as financing, and is not sustainable as few grants support on-going operating costs.

Emerging opportunities include working Medicaid, Medicare Advantage plans, and payers to develop palliative care reimbursement or benefit options.

Palliative care **remains challenging in rural communities** where they may only be **two or three patients per payer** leading some providers to consider not billing due to **administrative hurdles**.

What we learned from the Center to Advance Palliative Care (Allison Silvers)

Since 2015, CAPC has been collecting ideas and approaches from diverse payers including Medicare Advantage Plans, Medicaid Managed Care, commercial insurers, integrated payer-providers, and full risk providers.

The following key lessons learned emerged from CAPC's research:

- It is critical to **identify the 'right population'** for palliative care.
- **Identify the payment model** that best supports the service needed by each population.
- **Payment models may serve different purpose and goals**, e.g., fee for service works well for assessments and consultations.

Payment models should be variable. Using a gas burner as an illustration, payments should be able to 'dial up' for higher intensity care, and 'dial down' for lower intensity care. [measure more of the needs of the patients, lack of social support, many symptoms, someone who knows what their goals of care may need less]

Common payment models include: [expand explanation for non-knowledgeable]

- **Fee-for-service**, typically used for assessment and consultation
- **Episodic payments**, typically for 30-, 45- or 60-day periods; recertify if additional services needed
- Monthly bundled, **per member per month,** is a 'go to' payment model for many payers
- **Tiered bundled**, may become the next popular option. High, medium, and low depending on patient needs
- **Financial incentives** for inpatient palliative care

Financial incentives in general seek to influence provider behaviors whether clinician, hospital, specialty care, or palliative care. Incentives should be based on quality measures including:

- **Access** to care
- Patient **satisfaction**
- **Advance care planning**
- Clinical **quality**

The goal for payments is to strive for consistency across payers.

What we learned from Hawaii's Palliative Care Journey (Torrie Fields)

It took Hawaii **22 years** to fully develop their palliative care benefit. Torrie Fields, CEO of Votive Health, shares Hawaii's experience.

Palliative care shows **high customer satisfaction** but sees **low adoption when people are unfamiliar** with the services available, or that palliative care is covered by insurance.

Palliative care is in line with what patients want, namely **improving health equity** for individuals with serious illnesses, **improving access to high-quality serious illness care**, and **improving quality of life** for the patients and their families.

Key decisions Hawaii used to develop their benefit included:

1. Determine the **policy route** to take [what is the process to create the cost and business case for filing a state Medicaid benefit for these services.
2. Identify the **population in need.**
3. Set a **baseline** based on past experience.
4. Determine **how many people** might access services.
5. Determine the **cost of the services offered**.
6. Determine if the **costs can cover services delivered** and **how much the state can afford**.

Questions to determine **impact on cost and savings** included:

COST Assumptions

- **What population** will be covered?
- **Who will benefit** most from services?
- **How many people** will access care?
- How **long will people be receiving care**?
- How **will other services be impacted**?

SAVINGS Assumptions

- **What is being avoided** by delivering this care?
- **What services will be accessed sooner** because of this care?

Appendix E. Serious Illness Action Network August Summit Agenda

Palliative Care Summit: Practice Policy and Payment
August 12 & 13 2021 9:00 – 12:00
Day 2 Agenda

Time	Topic	Speakers
9:00	Welcome and Introductions	**Jennifer Lundblad, PhD** President and CEO, Stratis Health **Jessica Hausauer, PhD** Executive Director, Minnesota Network of Hospice and Palliative Care
9:10	Policy and Payment Recommendations from the Minnesota Palliative Care Advisory Council	**Jessica Hausauer, PhD** Chair, Minnesota Palliative Care Advisory Council
9:20	Payment Design and Changes Needed to Grow Rural Palliative Care	**Karla Weng, MPH, CPHQ** Senior Program Manager, Stratis Health's Rural Initiatives
9:35	Best Practices in Palliative Care Payment and Access	**Alison Silvers, MBA** Vice President for Payment and Policy, Center for Advance Palliative Care
10:05	Small Group Discussion	All
10:30	One State's Approach: Improving Quality through a Sustainable Community Based Palliative Care Benefit	**Torrie Fields, MPH** Founder and CEO, Votive Health
11:00	Small Group Discussion	All
11:20	Large Group Discussion	All
11:30	Panel Discussion: Taking Action to Advance Palliative Care Policy and Payment in Minnesota	**Senator Karin Housley** Chair, Aging and Long-Term Care Policy **Representative Liz Reyer** Member, Health Finance and Policy **Patrick Courneya** Chief Health Plan Medical Office HealthPartners **Gretchen Ulbee** Minnesota Department of Human Services
11:55	Next Steps & Closing	All

Appendix F: Serious Illness Action Network November Agenda

Serious Illness Action Network Fall Forum on Caregiving
November 8, 2021 1:00 – 3:00

Time	Topic	Speakers
1:00	Welcome and Introductions	**Jessica Hausauer, PhD** **Jennifer Lundblad, PhD**
1:05	Bridging the Family Care Gap	**Joe Gaugler, PhD** Professor and Robert L. Kate Endowed Chair in Long-Term Care and Aging, School of Public Health, UMN
1:15	Caregiving as a Social Determinant of Health	**Jennifer Olsen, PhD** CEO, Rosalynn Carter Institute for Caregivers, Health & Aging Policy Fellow
1:30	Recognize, Assist, Include, Support & Engage (RAISE) Family Caregivers Act Report to Congress	**Beth Wiggins, MSW, LISW** Director of Caregiving and Aging Services, FamilyMeans
1:40	Breakout Session	
2:00	Panel: Caregiver Services & Supports	**Dawn Simonson** Executive Director, Trellis **Sheryl Fairbanks** Co-Creator, Dementia Caregiver Re-entry Initiative **Dorothea Harris** Director, Culturally Responsive Caregiver Support & Dementia Services, Volunteers of America
2:30	Breakout Session	
2:40	Recommendations, Next Steps & Closing	

Appendix G: Council Members

2021 Palliative Care Advisory Council Members

Name	Seat	Term End Date
Erin Balbach	Registered Nurse or Advance Practice Nurse	10/1/2022
Jody Chrastek	Registered Nurse or Advance Practice Nurse (NBCHPN Certified)	10/1/2023
Karen Gervais	Member	10/1/2023
Audrey Hansen	Member	10/1/2022
Jessica Hausauer	Patient or Personal Caregiver, Chair	10/1/2023
Intisar Hussein	Licensed Social Worker	10/1/2022
C Scott Kammer	Health Plan Representative	10/1/2023
Merryn Jolkovsky	Care Coordinator	10/1/2023
Deborah Laxson	Patient or Personal Caregiver, Vice-Chair	10/1/2022
Joe Amberg	Physician	10/1/2022
Elizabeth Mahan	Care Coordinator (Spiritual Counselor)	10/1/2022
Julie Mayers Benson	Physician (ABHPM Certified)	10/1/2023
Carol Shapiro	Patient or Personal Caregiver	10/1/2022
Dannell Shu	Patient or Personal Caregiver	10/1/2023
Adine Stokes	Licensed Health Professional	10/1/2022
Virginia Thompson	Licensed Health Professional	10/1/2023
Karen Wald	Licensed Health Professional	10/1/2022
OPEN SEAT	Physician Assistant (ABHPM Member)	--

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.