

# Palliative Care Advisory Council

PROGRESS REPORT 2018

## **Palliative Care Advisory Council 2018 Progress Report**

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# Executive Summary

In 2017, the legislature established a Palliative Care Advisory Council for the State of Minnesota. By law, the Council must assess the availability of palliative care in the state of Minnesota, analyze barriers to greater access to palliative care, and make recommendations for legislative action. By February 15 of each year, the Council is required to report on its progress. This report provides an introduction to palliative care, updates the status of the Council, provides preliminary reporting on the availability of palliative care in Minnesota, and outlines the Council's next steps.

To assess the availability of palliative care in Minnesota, this report provides data on hospital-based palliative care, the numbers of hospice and palliative care certified physicians and nurses, and public awareness of palliative care. While the data is limited, results show:

- 61% of Minnesota hospitals offer palliative care services, compared to 59% of hospitals nationally
- Availability of hospital-based palliative care is greater in urban areas
- We do not yet have data on the availability of community based palliative care in MN
- Minnesota has 226 Hospice and Palliative Certified physicians, 41 Advanced Certified Hospice and Palliative Nurses, and 232 Certified Hospice and Palliative Nurses
- Over two-thirds of Minnesotans demonstrate no knowledge or familiarity of palliative care

While this report provides a brief overview of palliative care data for Minnesota, the Council will continue to gather and study palliative care data for Minnesota. There are plans to develop a robust assessment of Minnesota's need, availability and access to palliative care services. The Council will also assess the barriers to care. From this data, the Council will analyze factors that could be considered for legislative impact. In addition, the Council will continue to define its governance structure and will embark on strategic planning to ground itself as an advisory body.

# Introduction to Palliative Care

Palliative care (pronounced pal-lee-uh-tiv) is designed for symptom management for chronic or serious illness at any stage of life. While a key component of excellent end of life care, it is sometimes mistakenly associated solely with hospice or end of life care. It can be provided along with curative treatment. Optimally provided through a team approach, palliative care focuses on providing relief from the pain, symptoms, and stress of a serious illness in order to maximize quality of life for the patient, and the family as well. Palliative care teams do so by early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems (ICSI, 2012).

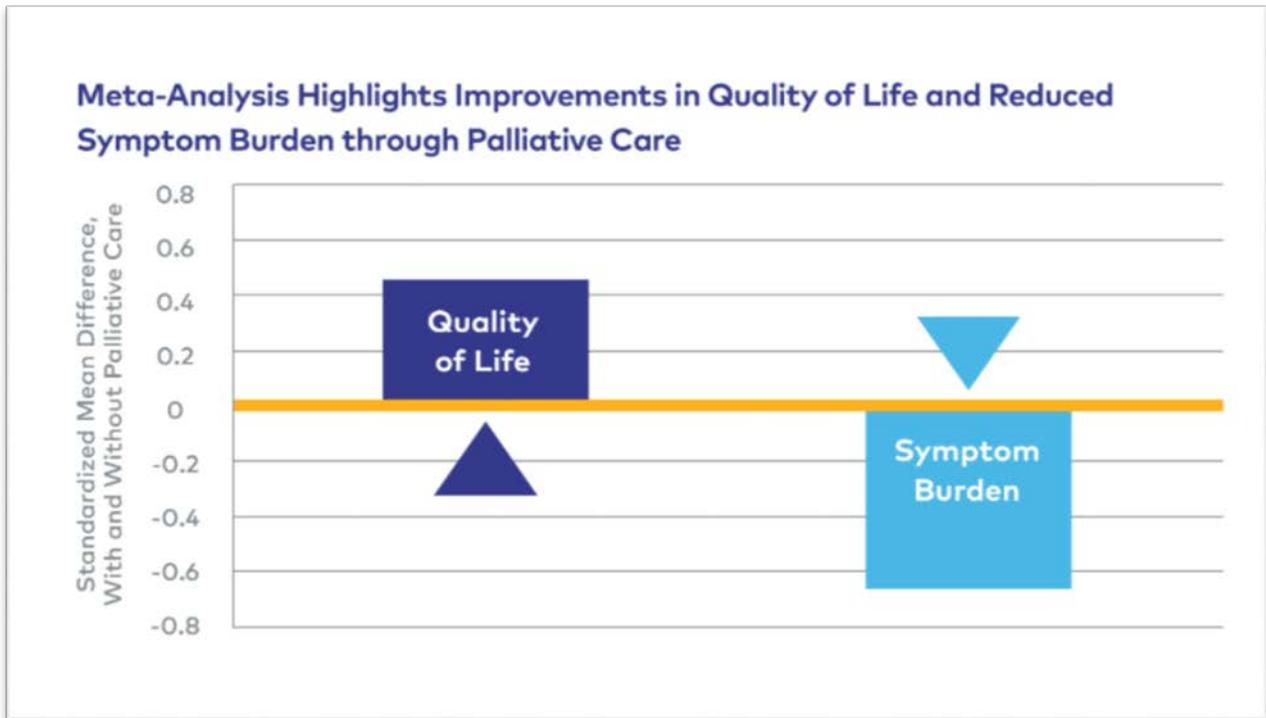
The [Center to Advance Palliative Care Mapping project](#) (CAPC, 2017) has created a definition, adapted from WHO (2008-2012) and the Palliative Care National Consensus project (2004-2012), that at a minimum, a palliative care program provides:

- Expert pain and symptom management
- Effective communication with patients and families to support their decision-making for medical treatment and care priorities
- Screening and support for the emotional, social, and spiritual needs of patients and their families

These Palliative Care Programs can often be called "supportive care," "advanced care", "advanced illness management", or "serious illness care" programs.

## Why Palliative Care

There is significant research demonstrating the effectiveness of palliative care. Palliative care has been shown to increase survival and improve quality of life in patients with serious illnesses (Temel, 2010). The graph below shows a visual representation of these benefits. Beyond patients, caregivers are also more satisfied with the care provided (McDonald, 2017). In addition to benefits for patients and their caregivers, palliative care has been found to be less costly relative to comparator groups in a meta-analysis (Smith S, 2014). For example, a study of Medicaid spending at four New York state hospitals comparing those receiving palliative care and a matched group showed an average \$6900 reduction in costs for those receiving palliative care (Morrison, 2011). In summary, palliative care has been shown to offer benefits for both patients and caregivers while at the same time reducing costs.



(Kavalieratos D, 2016).

## Status of the Palliative Care Council

In 2017, the legislature authorized the creation of a Palliative Care Advisory Council under [Minnesota Statutes, section 144.059](#). It charged the Council with assessing, analyzing and making recommendations to the legislature on issues related to palliative care for Minnesota. Its membership includes health professionals who have palliative care work experience with patients of all age groups or expertise in palliative care delivery models from inpatient, outpatient and community settings, including acute care, long-term care and hospice. The Council also includes patients and family caregivers with firsthand experience with palliative care.

There were over 75 applications to the [Office of Minnesota Secretary of State](#) for the Council. An external review team ranked applications, and the Commissioner of Health made final appointments. Nineteen applicants were appointed. Appendix A provides a listing of the appointees and the type of appointment that they hold. Appointments are staggered between two and three years.

Since the October 1, 2017 appointment, the newly formed Palliative Care Advisory Council has had two meetings in 2017 and one meeting in January 2018. The Council has appointed a chair and vice-chair and has established a monthly meeting schedule on the 2<sup>nd</sup> Wednesday of every

month from 5 to 7 PM. Work teams are forming, and by-laws will be developed over the next several months.

The Council is embarking on a strategic planning process to ensure that it develops a state palliative care plan that includes:

- Assessment of the availability of palliative care in MN
- Analysis of the barriers to access
- Recommendations to improve access to palliative care

The Minnesota Department of Health’s Comprehensive Cancer Control Unit has been assigned to assist the Council with carrying out its legislative mandate. Communication around the business and work of the Council is documented on the MDH website, with specific content pages related to [palliative care](#) and the [Palliative Care Advisory Council](#). All meeting agendas and notes are published through the latter’s webpage, allowing us to ensure compliance with the open meeting law. In addition to council members, attendees from the general public have attended meetings. MDH also supports an internal online platform for the sharing of documents and work through SharePoint. This is accessible to appointed council members and staff.

# Palliative Care in Minnesota

## **Availability: What We Know**

### **Hospital-Based Palliative Care**

In 2011, a report by the National Palliative Care Research Center showed that 89% of Minnesota’s large hospitals provided palliative care services while only 37% of hospitals with fewer than 50 beds did (Care, 2011). In 2015, the National Palliative Care Registry reported that 61% of Minnesota’s hospitals provide palliative care compared to 59% nationally. As shown in their tables on page 7, the availability of palliative care varies by size and community. Larger hospitals and those hospitals in urban areas, are more likely to provide palliative care (CAPC & NPC, 2015). While geographic disparities continue to exist, it appears that palliative care services have significantly increased in rural areas in Minnesota since 2011.

### Hospital-Based Palliative Care in Your State\*

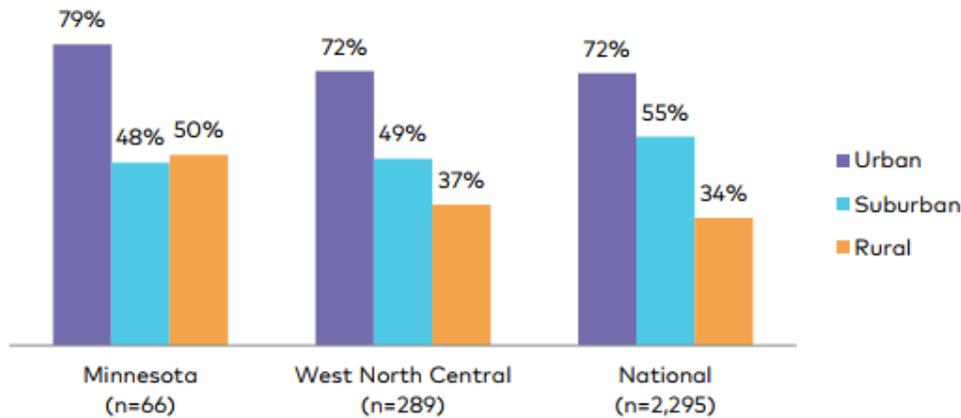
The availability of palliative care services in U.S. hospitals varies widely by state and region. Most large hospitals now offer palliative care services.

Location	Total Programs/ Hospitals	By Hospital Size			
		<50 beds	50-150 beds	151-300 beds	300+ beds
Minnesota	61% (66/108)	55% (31/69)	76% (13/17)	100% (9/9)	100% (13/13)
West North Central Region	50% (289/575)	36% (139/388)	68% (57/84)	87% (45/52)	94% (48/51)
National	59% (2,295/3,888)	38% (509/1,508)	60% (540/904)	77% (580/756)	93% (666/720)

West North Central = IA, KS, MN, MO, NE, ND, and SD

### Percentage of Hospitals with a Palliative Care Program by Community Type

Hospital-based palliative care is less common in rural communities. Nationally, 34% of rural hospitals provide palliative care compared to 72% of urban hospitals.



\*Data on hospitals with palliative care were obtained from the American Hospital Association (AHA) Survey Database™ and the National Palliative Care Registry™. For both, the most recent and complete data available are for 2015.

(CAPC & NPC, 2015)

In 2007, Stratis Health convened a group to explore the challenges surrounding rural palliative care. In 2008, Stratis Health began providing active support to 23 rural communities. Stratis Health released its Rural Palliative Care Impact Report in July 2016 (Stratis Health, 2016). Some of their key findings regarding rural palliative care programs are:

- Health care organizations in rural communities can provide palliative care services effectively. The models for service delivery can and do vary widely.
- For most rural communities, external resources and support are necessary to support community-based palliative care services.
- Ongoing networking for learning and sharing is critical to program sustainability.
- Defining community-based metrics is essential to quantify the impact of palliative care on cost, quality of care, and patient and family satisfaction.
- More widespread reimbursement for palliative care services would contribute significantly to the sustainability of programs in rural communities.
- Development of palliative care programs and services must align with other efforts to redesign care delivery and reimbursement to maximize efficiency for rural providers.

While hospital palliative care and hospice are more widely available, access to palliative care in other settings is also desirable. There is currently an assessment underway to map the availability of community-based palliative care in the United States. (CAPC, 2017) The Palliative Care Advisory Council hopes this information will provide a more robust assessment of community-based palliative care access in Minnesota.

### **Health Professional Availability: Professional Certification**

According to the American Board of Medical Specialties, 226 physicians are certified in palliative care in Minnesota. However, not all physicians listed in the certification directory practice in Minnesota (ABMS, 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 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. The quantification of this care is not known at this time.

### **Public Awareness of Palliative Care in Minnesota**

The Minnesota Network of Hospice & Palliative Care conducted the first comprehensive statewide survey of end-of-life needs of older Minnesotans in 2011. The survey found that 68% of 400 Minnesotans ages 50-80 had no knowledge of, or 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).

# Palliative Care Advisory Council 2018 Impact Agenda

The Palliative Care Advisory Council held its first meeting in November 2017. The Council is currently focused on creating the governing infrastructure for the Council and creating its strategic plan through 2025.

## **Next Steps**

Over the course of the next year, the Council will focus on four main priorities for palliative care in Minnesota:

1. Define the long-term 2025 vision, or the “to be” state;
2. Document the gaps between the “as is” (2018) and “to be” state (2025);
3. Create a strategic plan to reduce the identified gaps between “as is” and “to be” states of palliative care. The strategic plan will include the goals, objectives, strategies required to successfully implement the long-term vision and fulfill its legislative mandate. The plan will include monthly deliverables through June, 2019, quarterly deliverables for July, 2019 through December, 2020, and annual deliverables for 2021 through 2025; and will be reviewed no less than annually; and
4. Determine the working infrastructure (e.g. by-laws) required for the Council to successfully achieve the legislative directives for and the long-term visions of the Palliative Care Advisory Council.

The formation of a strategic plan will provide direction and guidance for the Council for the next year, and beyond. It will allow for the flexibility needed to respond to evolving changes within the Council membership, as well as in the legislative, medical and social communities.

# Appendix A:

## Palliative Care Advisory Council

### Members

**1 Physician certified by American Board of Hospice and Palliative Care Medicine**

Dr. Julie Mayers Benson, MD

**1 Physician**

Dr. Kirstin LeSage, MD

**1 Registered Nurse certified by National Board for Certification of Hospice and Palliative Care Nurses**

Joan Chrastek, RN, DNP, CHPN, FPCN

**1 Registered Nurse**

Rebecca Weber, MSN, NP-C, APRN, CPM

**1 Care Coordinator**

Patrice Moore, RN, OCN, BSN

**1 Spiritual Counselor**

Elizabeth Mahan, DMin, BCC

**3 Licensed Health Professionals**

Ginger Thompson, Pharmacist

Mark Burnett, MT-BC, Music Therapist

Adine Stokes, LSW

**1 Licensed Social Worker**

Mindy Wise, LICSW

**4 Patient or Caregiver**

Jessica Hausauer, PhD

Dannell Shu

Deborah Laxson

Carol Shapiro

**1 Representative from Health Plan**

Dr Howard Epstein, MD, SFHM

**1 Physician Assistant member of American Academy of Hospice and Palliative Care Medicine**

Ryan Baldeo, MPAS, PA-C

**2 Member at Large**

Karen Grandstrand Gervais, PhD

Karen Wald, MS, CCC-SLP

**Student Designation**

Joy Liu

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