



KANSAS PALLIATIVE CARE

5-Year State Plan

2022-2027



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Executive Summary

Palliative care is comprehensive, interdisciplinary care for patients living with serious, potentially life-threatening or life-limiting conditions, with the goal of improving quality of life for both the patient and family. This approach to care prevents and relieves suffering through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care is delivered based on needs, not prognosis. It is appropriate at any age or any stage of an illness and can be delivered along with curative treatment.

The Palliative Care and Quality of Life Interdisciplinary Advisory Council was established by legislation in 2018 to:

- Make recommendations to and advise KDHE on the establishment, maintenance, operation, and outcomes evaluation of palliative care initiatives in the state
- Maximize effectiveness of the State Palliative Care Consumer and Professional Information and Education Program
 - The program serves to ensure availability of comprehensive and accurate information and education about palliative care for all Kansans.

At present, availability and delivery of quality palliative care in the state of Kansas is lacking. According to the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC), Kansas' access to palliative care currently ranks last in our region and 42 of 51 states and the District of Columbia. Data from 2021 Kansas Behavioral Risk Factor Surveillance System showed that only 3.6% of adult Kansans had received palliative care. To improve the provision of palliative care within Kansas, the council has identified the following four areas of priority:

- Access
- Education and Health Care Workforce Training
- Public and Community Awareness
- Emergency Preparedness and Disaster Planning

Key Takeaways to Improve the Care of Kansans with Serious, Potentially Life-threatening or Life-limiting Conditions.

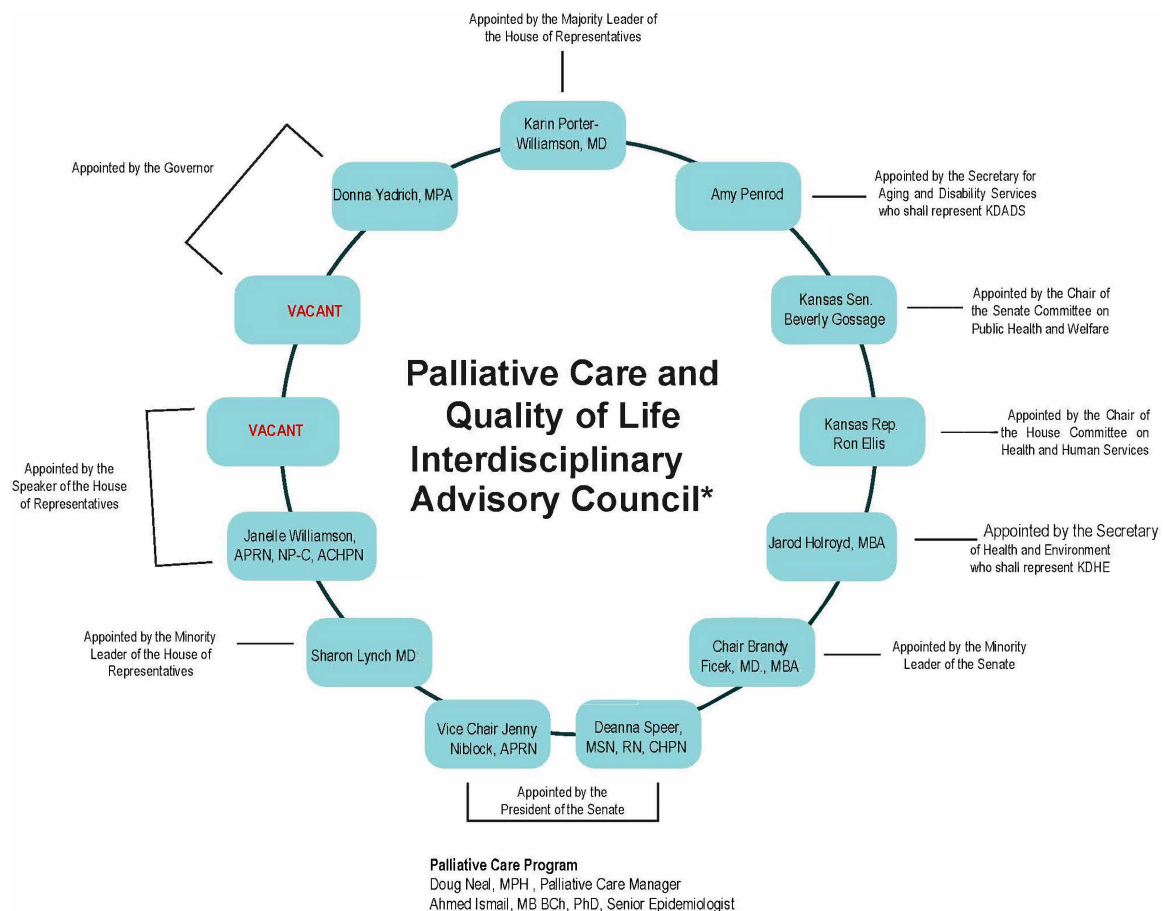
1. Expansion of broadband access and preservation of policy changes for delivery of telehealth services are essential in order to achieve access to timely palliative care for all Kansans, including those in rural and frontier communities.
2. Incentive programs to recruit, train and retain highly skilled palliative care clinicians, education on primary palliative care for all disciplines, and enhanced support for unpaid caregivers are crucial in order to address our State's palliative care workforce shortage.
3. Efforts to engage and inform Kansans about palliative care are necessary in order to improve the general public's understanding and acceptance of palliative care, especially its differentiation from hospice.
4. Efforts to bring advance care planning and serious illness care planning to scale across care settings are necessary, so that Kansans are well informed and can express their wishes, values and treatment preferences.

Palliative Care and Quality of Life Interdisciplinary Advisory Council

Legislative Establishment

In 2018, the Kansas Governor signed legislation introduced as HB2031 that established both a Palliative Care and Quality of Life Interdisciplinary Advisory Council (PC-QOL) as well as the State Palliative Care Consumer and Professional Information and Education Program, supported by Kansas Statutes Annotated (K.S.A.) 65-1260 and 65-1261.

Kansas' Palliative Care and Quality of Life Interdisciplinary Advisory Council is comprised of 13 appointed members. Current membership includes:



Responsibilities

The Council is tasked with evaluating and providing recommendations to the Kansas Department of Health and Environment on matters related to the establishment, maintenance, operation and outcomes evaluation of palliative care initiatives in the state, as well as the effectiveness of the palliative care consumer and professional information and education program.

Accomplishments

Development of Bylaws and Vision Statement

Upon commencement in late 2018, the Council established bylaws to provide a guiding structure for its efforts and created a unified vision. The vision of the Council:

To ensure that all Kansans living with serious, potentially life-limiting illness have access to quality palliative care.

Four Areas of Priority Identified

The initial work of the Council has been to identify barriers and opportunities within three core areas of focus to achieve this goal. These areas include:

1. Access
2. Education and Health Care Workforce Training
3. Public and Community Awareness

In addition, the COVID-19 pandemic drew intense attention to the need for the inclusion of palliative medicine within the greater scope of health care during emergent or disaster situations. Thus, a fourth area of focus to help address these key issues was added to the Council's strategic plan.

4. Emergency Preparedness and Disaster Planning

Development of Palliative Care Branding, Website and Small Media Resources

In partnership with KDHE Communications the PC-QOL created small media, website and logos.

Determination to Produce a State Plan

Committees evolved from this core framework in order to better assess needs, monitor key legislative issues, and make recommendations to the full Council for consideration for inclusion in the state plan.

Following approval, this plan will offer guidance for future advisory council efforts, inform key stakeholders of crucial policy issues, and invite statewide discourse. Together, this work will serve to move our state toward the goal that all Kansas families facing serious illness have the information and opportunity to obtain high quality medical care aligning with their unique circumstances and values.

Collaboration with University of Kansas Medical Center Project ECHO

Case-based learning using Project ECHO (Extension for Community Health care Outcomes) delivered two continuing medical education series:

- *Palliative Care ECHO 2022: Establishing a Kansas Community of Practice to Improve Lives of People Experiencing Serious Illness*
 - 200+ participants across Kansas attended the 4 courses in June 2022.
- *Palliative Care ECHO 2022: Pain Management for People Living With Serious Illness*
 - 138 participants across Kansas attended the 5 courses in October 2022.

Palliative Care Overview

Palliative Care and Serious Illness Defined

Palliative care provides comprehensive, interdisciplinary care aimed at improving symptoms and quality of life for patients and families facing serious, potentially life-limiting illness. Palliative care's approach is to use expert symptom management, skilled communication, and promotion of shared decision-making to treat each person. The care addresses not only the physical aspects of care, but also the emotional, spiritual and social needs associated with serious illness. Palliative care may be provided for patients of any age from diagnosis throughout the course of the illness, at the same time as other treatments. Examples of diagnoses appropriate for palliative care include advanced dementia, cancer, chronic obstructive lung disease, genetic disorders, perinatal conditions, heart conditions, HIV/AIDS, kidney disease, liver disease, multiple sclerosis, neurologic disorders, among others.

Indeed, diagnosis alone often fails to identify the highest needs patients. Those people *most* likely to benefit from Palliative care interventions are those who are living with a combination of diagnosis of an advanced illness, plus:

- 1) increased need for access to medical care/providers/hospitalization
- 2) increased need for support from formal and informal caregivers

This population of people fits an inclusive definition of serious illness, defined as “any 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, 2018).

These patients often experience inadequately treated physical distress, difficulty navigating fragmented care systems, poor communication between physicians and families, and strain on their support systems. In addition, this segment of the population often accounts for significant health care utilization and costs due to interventions and care that are not aligned with patient preferences (Meier, 2011).

Proven Benefits of Palliative Care

Palliative care has been shown to improve:

- Quality of life
- Caregiver burden and depression
- Symptom distress
- Documentation of resuscitation preferences
- Patient satisfaction
- Survival in select populations

Because of these and other benefits, many specialties that treat patients with serious illness advocate for the increased availability of palliative care. The American Society for Clinical Oncology (ASCO), American Heart Association (AHA), American Stroke Association (ASA), and American Thoracic Society (ATS) have all released guidelines that highlight the importance of integrating palliative care into the standard of care for their respective patient populations.

Although not the primary aim, palliative care also indirectly reduces the burden on the health care system, demonstrating decreases in hospital and acute care utilization. Delivery of care consistent with patients' values and avoidance of unwanted treatments leads to reduction of health care costs. For inpatient palliative care consultations, cost savings estimates are as much as \$3,000 to \$4,800 per admission, and up to \$7,000 of savings in the Medicaid population (May 2018; Morrison 2011). Yet another study estimated annual savings of \$11,508 per patient enrolled in an outpatient palliative care program (Cunningham, 2016).

The demonstrated benefits of palliative care easily satisfy each of the three dimensions of the Institute for Health care Improvement's "Triple Aim" – patient experience, population health, and per capita cost. However, palliative medicine continues to face many barriers that impede widespread utilization. Thus, as we look to deploy palliative medicine as an overarching strategy to improve overall health care outcomes for Kansas residents, we must address these barriers.

Patient Vignette

My name is Theresa Meyer and I have been living with breast cancer since 1998. After a period of remission, my breast cancer returned in 2013. I was diagnosed with terminal Stage IV Breast Cancer. I initially established my oncologic care in the Kansas City area, 180 miles from my home. Eventually I was able to obtain care closer to home in Manhattan, Kansas.

After years of maintenance therapy, my quality of life began to decline. I suffered from depression, poor appetite, low energy levels, severe weight loss, and pain. My husband became my caregiver, performing all the household duties.

Through my volunteer work with the American Cancer Society Cancer Action Network, I had the opportunity to work alongside a palliative care nurse practitioner who encouraged me to talk with my doctor about receiving palliative care. Unfortunately, in the community of Manhattan, I did not have access to specialty palliative care services. It was suggested by my oncologist to stop my treatment and enroll in hospice, but I knew as a former hospice volunteer that I was not ready for hospice care, let alone qualify for this type of care.

Eventually, I was able to connect with a palliative care team in Lawrence, Kansas.

Within a year of establishing care with a palliative care specialist, my quality of life was back! I wanted to live again. All the things that had slowly disappeared from our lives were back again! I now drive 4 hours round trip to attain this type of care. It is my hope that palliative care will be easily accessible for all Kansans someday soon!

Access

Delivery of high-quality palliative care services addresses many issues facing health care today. The need to improve value in medical care through increased quality while achieving cost savings, and the call for patient centered care models to meet the complex needs of seriously ill patients and their caregivers are just two issues that palliative care addresses. Despite significant data showing these benefits, access to palliative care in the state of Kansas remains a significant barrier.

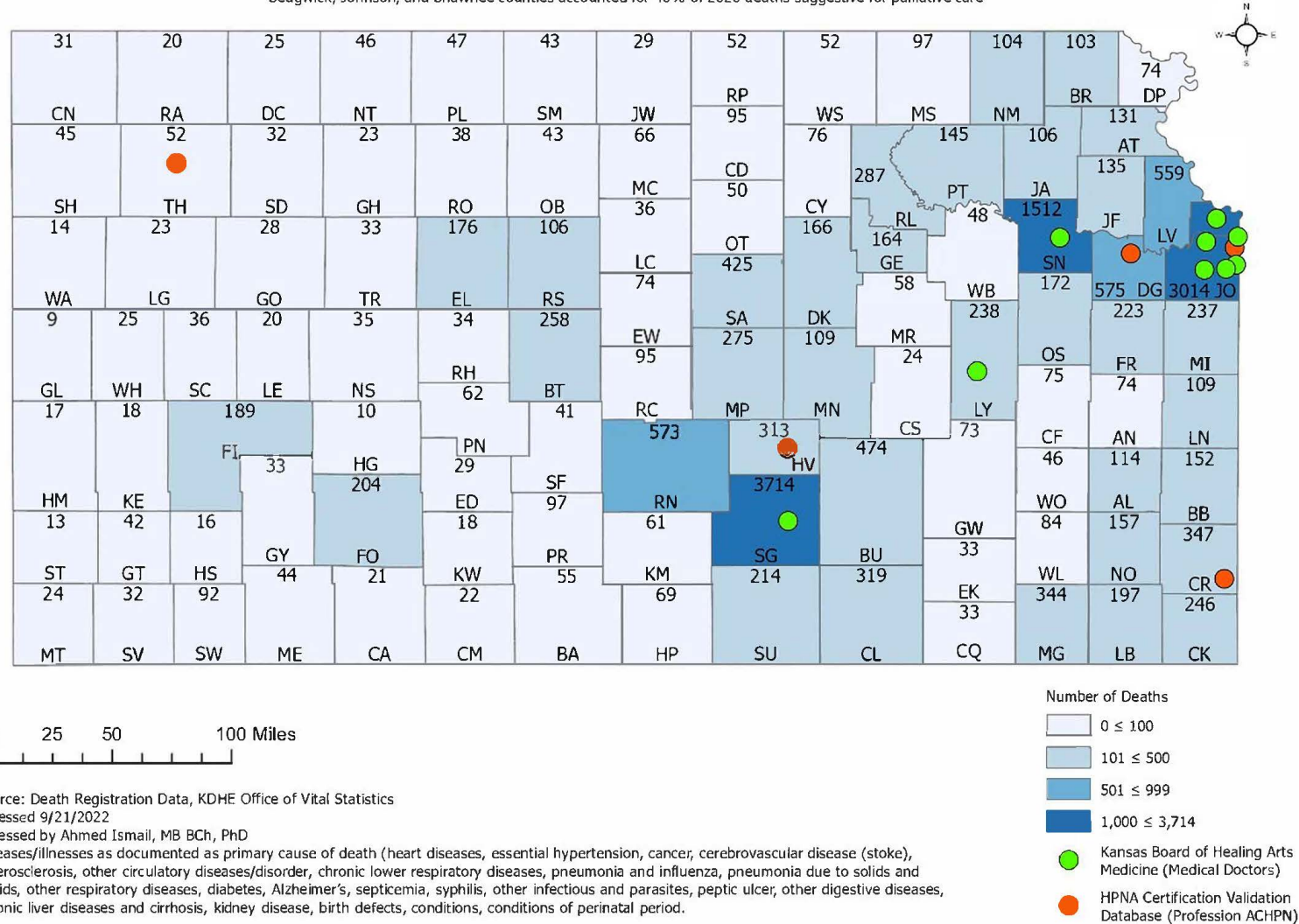
Needs within Our State

As palliative care treats a wide range of conditions and can be implemented at any time along the trajectory of care, it can be difficult to ascertain precise data regarding the number of patients and families in need of palliative care services. However, despite the lack of a universally defined mechanism to determine needs, several proxy measures are used to provide estimates of the number of patients facing serious illness.

Annual mortality information from non-accidental and non-infectious causes provides an estimate of patient needs, as patients with serious illness and heavy symptom burden often have prognoses limited to one year or less. In 2020, Kansas deaths from non-accidental and non-infectious causes totaled 20,853. The map below demonstrates this information by county.

Kansas Mortality as a Proxy for Need of Palliative Care, 2020

Sedgwick, Johnson, and Shawnee counties accounted for 40% of 2020 deaths suggestive for palliative care

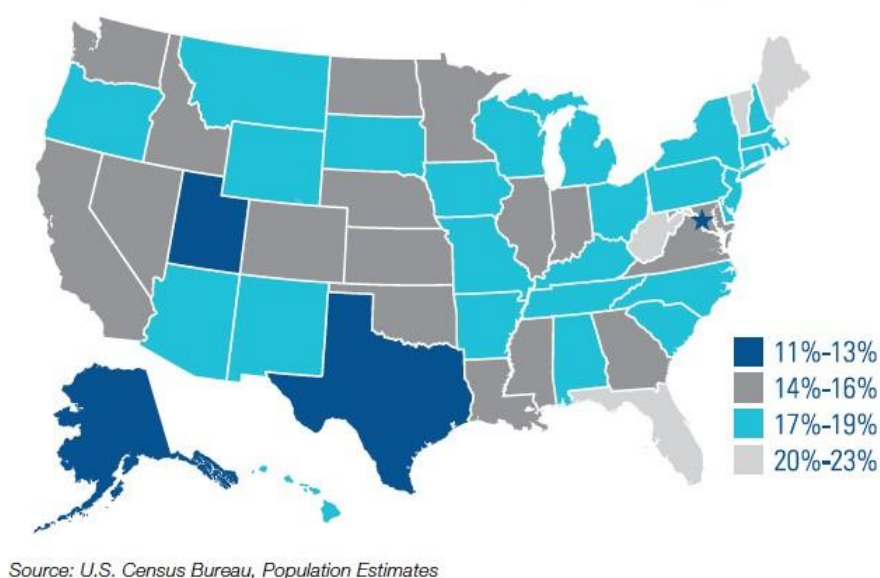


Additionally, it can be helpful to consider some of the most frequent diagnoses referred to palliative care for further approximation of overall needs. According to the World Health Organization, the two most common diagnoses in need of palliative care are cardiovascular disease and cancer. In Kansas, 3.7% of the 2019 population or 107,792 persons, were living with heart failure and it is currently the leading cause of death in the state (BRFSS, 2019; Population Statistics, Vital & Health Statistics).

According to Kansas Cancer Registry data from 2008-2017, approximately 15,000 invasive cancers were diagnosed each year. Examining these two diagnoses alone demonstrates that there are thousands of Kansans possibly in need of palliative care services.

As serious illness becomes more common with age, the growing senior population in Kansas also demonstrates a growing need for palliative care in order to support the needs in our communities.

Persons Age 65 and Older as a Percentage of Total Population, 2019



In 2019, those aged 65 and older totaled 54.1 million in the United States. In Kansas, this total was 475,487, which is 16.32% of the total state population. Both totals are expected to grow as the number of older adults is projected to increase to 80.8 million by 2040. (2020 Profile of Older Americans)

Although adults with serious illness are most commonly evaluated for the need for palliative care, the pediatric population can also benefit from these services. Children can experience congenital, genetic, or malignant life threatening or life limiting conditions and 50% of rare diseases affect children. It remains difficult to estimate the magnitude of this need. However, 1 in 5 children have special health care needs which consume 80% of pediatric health care costs (National Survey of Children's Health, 2020). Many of these children have serious medical problems and would benefit from palliative care. In Kansas, based on 2020 U.S. census population estimates, this would indicate that there are over 141,000 children with potential palliative care needs.

Availability of Palliative Care in Kansas Ranks Near Bottom of the U.S.

Inpatient 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*. This report tracks access to palliative care in all 50 states and the District of Columbia. States are assigned grades based on the percentage of hospitals with greater than 50 beds that have access to palliative care. The most recent version of the report was released in 2019. According to this report, In Kansas, only 56.7% of hospitals with greater than 50 beds provide palliative care. This affords Kansas a “C” grade regarding access to palliative care and ranks our state 42 out of 51 states and the District of Columbia. Within our assigned West North Central Region, Kansas ranks the lowest of the seven states. Notably, all five of Kansas’s largest hospitals with greater than 300 beds provided palliative care, however, only 27.2% of hospitals with less than 50 beds provided palliative care. This discrepancy highlights not only the overall lack of access to palliative care, but also the disparity in access between urban and rural communities.

There is also disparity in program composition and staffing. The Joint Commission (TJC) standards for advanced certification of palliative care programs directs that the provision of palliative care be provided by an interdisciplinary team that consists at a minimum of a licensed independent practitioner, registered nurse, chaplain and social worker. However, neither of the reports regarding palliative care within our state noted above used criteria to define what makes up a palliative care program. Thus, a program that has a full interdisciplinary team comprising a physician, advanced practice provider, nurse, social worker, pharmacist, and chaplain would count the same as a program that only has a social worker. Similarly, palliative care from a board-certified specialist counts the same as a general practitioner providing this care to their patients. The significant variation in program structure results in potential differences in the quality of care provided. Thus, even in areas where there is access to palliative care, the access may not be equal.

Community-Based Palliative Care in 13 Communities of 105 Counties

Besides the hospital setting, palliative care can be provided through community-based programs such as medical clinics, nursing homes, or home-based care. Since 2016, CAPC has attempted to track access to community-based programs through its *Mapping Community Palliative Care* project. They collected this information via a self-report survey, thus is unverified in contrast to their data on hospital-based palliative care. However, it provides the best approximation of community-based programs within the state. In 2021, the Mapping Community Palliative Care project lists two clinic-based, one nursing home, and 10 home-based programs within Kansas (GetPalliativeCare.org).

The combination of very few community-based programs and a significant rural population in Kansas leads to a significant burden for this population in seeking access to care. FY21 Data from the University of Kansas Cancer Center, located in the Kansas City metropolitan area, reveals that approximately 19% of their patients traveled over 50 miles to seek care, with 9.5% traveling over 100 miles.

Of 105 counties in Kansas, 37 are defined as “frontier” with a population density of fewer than six people per square mile. These areas of the state experience even more significant issues accessing health services and are often plagued by poor economic opportunities and other

conditions that result in health and social disparities. Consequently, the rural and frontier topography of the state results in a population that faces significant barriers to access not only palliative care, but to even the most basic of health care services.

Palliative Care Workforce

Due to an aging population and prevalence of serious illness in children and adults, multiple studies have indicated that the current palliative care workforce is not enough to meet the needs of our population. As of January 2016, there were just under 6,400 active hospice and palliative medicine physicians in the United States as reported by the American Medical Association. To put this in perspective, it was estimated that there was one palliative care physician for every 1,200 people living with serious illness, in contrast to one cardiologist for every 71 people having a heart attack and one medical oncologist for every 141 people newly diagnosed with cancer (Gelfman, 2017).

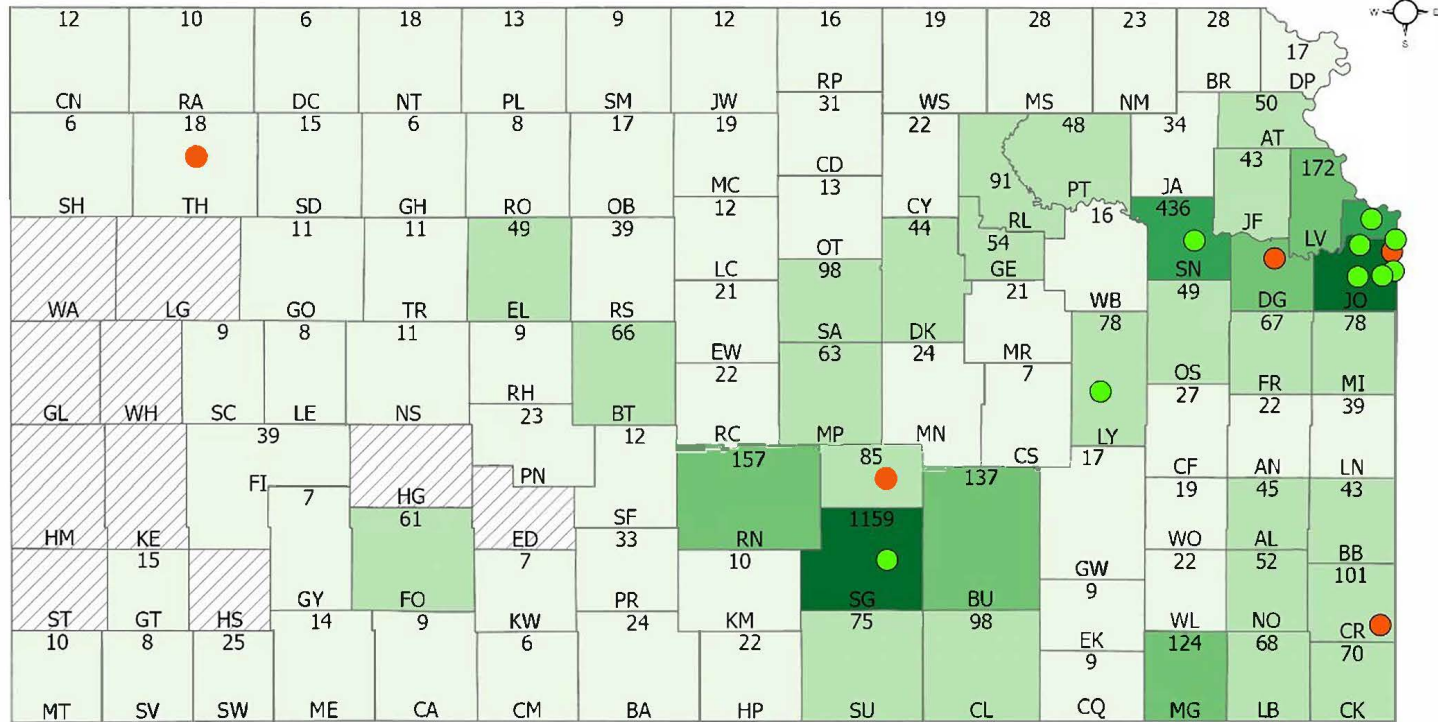
The exact number of physicians actively practicing palliative care within Kansas can be difficult to determine as methods by which governing bodies capture this information varies.

Based on current population estimates, and the best available data from KBOHA and HPNA, this equates to only 1.17 certified prescribing providers (MDs or APRNs) per 100,000 residents.

The American Board of Medical Specialties tallies a total of 62 physicians who hold board certification in hospice and palliative medicine but may practice in other areas such as anesthesia, family practice, internal medicine and pediatrics. According to data collected by the American Academy of Hospice and Palliative Medicine in 2016, there were only 26 physicians “actively” practicing in this specialty. As of 2021, according to the Kansas Board of Healing Arts (KBOHA), there are currently only 21 physicians actively practicing palliative care within our state. Further, according to the Hospice and Palliative Nurses Association (HPNA), Kansas has just 13 Advanced Certified Hospice and Palliative Care Nurses.

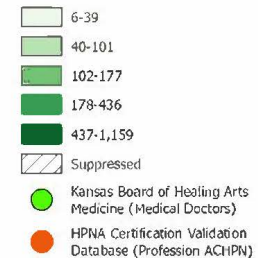
Not only are the total numbers of palliative care providers low, but the distribution within the state further accentuates the workforce shortage, especially in rural areas. When comparing the location of certified providers (MD, APRN) to areas showing the greatest rates of death from cardiovascular disease and overall cancer mortality, which are the two leading diagnoses related to palliative care need, it is easy to identify the lack of an adequate workforce that exists in the state of Kansas. In the frontier and rural areas of Kansas, there is a great reliance on primary care providers. Unfortunately, many of these providers lack the training, education and access to provide sub-specialty palliative care.

Kansas Heart Disease Mortality as a Proxy for Need of Palliative Care, 2020

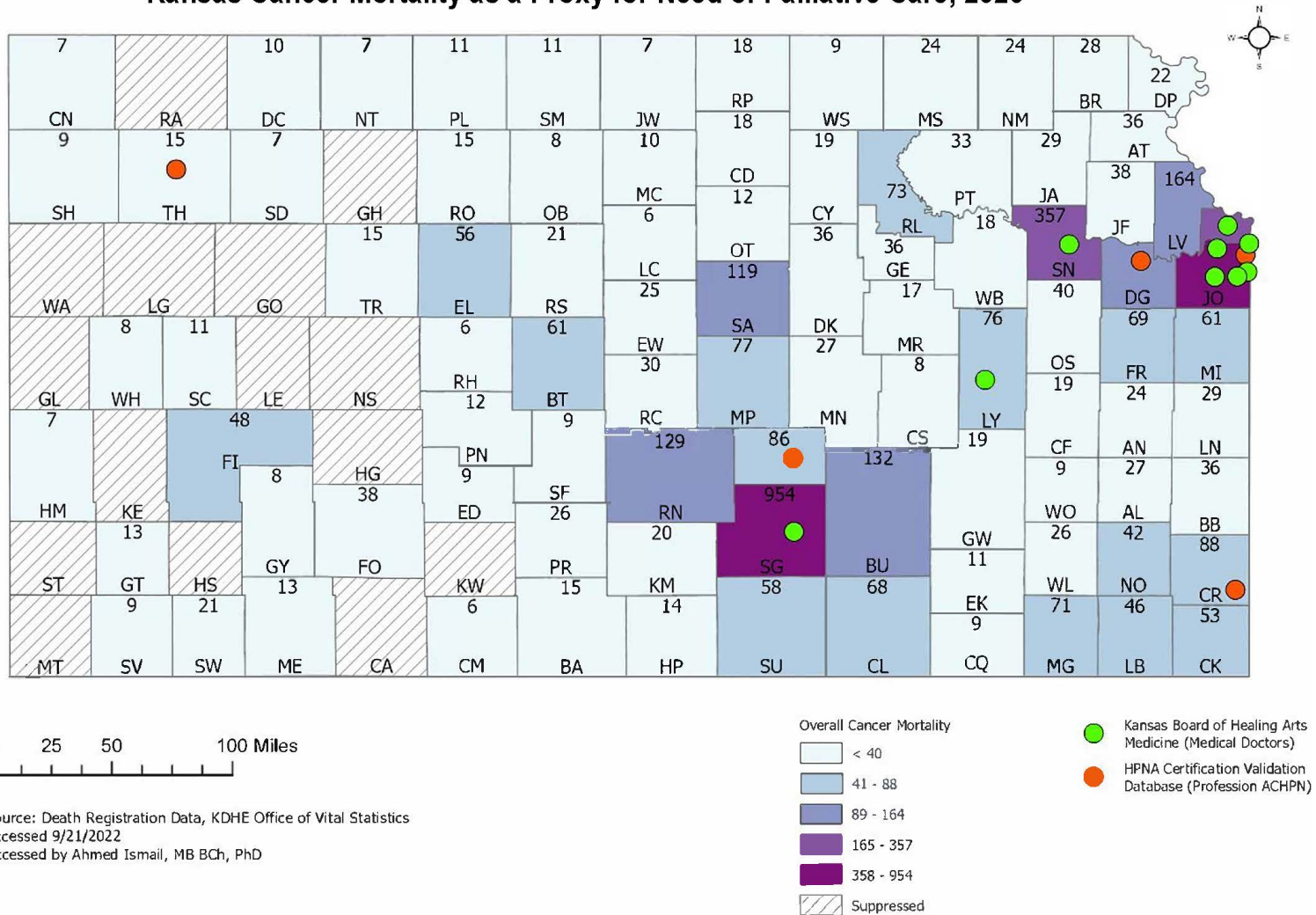


0 25 50 100 Miles

Source: Death Registration Data, KDHE Office of Vital Statistics
 Accessed 9/21/2022
 Accessed by Ahmed Ismail, MB BCh, PhD



Kansas Cancer Mortality as a Proxy for Need of Palliative Care, 2020



Interdisciplinary teams provide high-quality palliative care services and palliative care specialty certification is available for not only for prescribing providers but also for nursing, social work, and chaplaincy. Unfortunately, the number of these certified professionals in Kansas is also low compared to the estimated needs. As of 2021, there are 51 certified hospice and palliative care nurses, three certified hospice and palliative care licensed nurses, five certified hospice and palliative care nursing assistants and one nurse certified in perinatal loss. There are 680 Advanced Palliative and Hospice certified social workers in the United States, with Kansas having a mere three palliative care certified social workers to date. Data regarding certified chaplains is not readily available but is likely to be limited in the state of Kansas.

Pediatric Palliative Care

It is worthy to note that pediatrics is even further underrepresented in access to specialty palliative care. Prior to entry into the sub-specialization of palliative medicine, physicians first undergo training in one of many primary specialties, each with varied exposure to pediatrics. For example, those with primary certification in internal medicine do not receive any pediatrics training within their residency. Other specialties, such as anesthesia or physical medicine, may have limited pediatric training, as they typically require additional training to pursue a pediatric focus. Both pediatrics and family medicine require standard training to care for pediatric patients. Based on the best data, of current physicians practicing palliative medicine in Kansas, only two physicians are certified in family medicine and none in pediatrics, demonstrating the tiny proportion of practicing palliative medicine physicians with dedicated pediatrics exposure. In addition, presently, according to HPNA, there are no certified hospice and palliative care pediatric nurses in Kansas.

Reimbursement

Reimbursement remains a significant barrier to the provision of team-based palliative care. At present, palliative care reimbursement only includes what they billed for the palliative care specialist's evaluation and management (E & M codes) through a typical fee-for-service model. Unfortunately, because of the inability of other palliative care team members (registered nurses, social workers, and chaplains) to bill for their services, the revenue generated by a standard multidisciplinary palliative care team rarely covers their actual costs. Thus, additional funding sources are necessary. Although hospitals and health care systems often agree with the goals of palliative care, as well as the cost savings, they may vary in their ability and willingness to sponsor the full interdisciplinary team. This is especially true for for profit and critical access hospitals. In addition, the lack of reimbursement for the entire interdisciplinary team may disproportionately limit community-based programs, as they do not realize the same cost savings as larger hospital systems (Sullender, 2016).

Telehealth

Telehealth offers a unique opportunity to address workforce shortages, especially in rural areas, as providers do not need to be physically in the same area as their patients. In addition, telehealth provides an important mechanism of care specifically for the palliative care population and their caregivers, who often face greater burdens associated with in-person care because functional limitations and high frequency of visits.

In 2018, Kansas became one of over 30 states to require insurance coverage of telemedicine through The Kansas Telemedicine Act (KS HB2028). This law required private payers to cover telehealth services and allowed coverage under the State Medicaid program. However, adoption of telehealth remained low because of several limitations including:

- Private payers could set their own reimbursement fees, which were often significantly less than in-person visit.
- Audio-only visits were not a covered service.
- CMS required patients to be in a designated rural area and visit designated sites to access telemedicine technology.

However, changes to address these limitations were stimulated by the COVID-19 pandemic. During this time, CMS and private payers broadened access to telehealth on a temporary, emergent basis to facilitate widespread implementation during stay-at-home orders. Medicare and private payers paid for telehealth services at the same rate as regular, in-person visits.

Audio-only services became a covered expense, which was beneficial for those living in areas with unreliable internet or video capabilities, as well as elderly patients less amenable to the use of technology. Patients living in any area could receive these services from any location, including their own homes if they had access to an adequate internet connection. Several states, including Kansas and Missouri, loosened licensure requirements in order to allow for interstate telehealth to help address workforce shortages.

As of September 2021, these changes remain in place. However, as the changes were temporary, without further action the use of telehealth will once again be limited. During the pandemic, about 48% of patients utilized telehealth (James, 2021). While the experience was favorable for both providers and patients, it highlighted the poor broadband infrastructure in the state. Kansas ranks 28 in the nation in broadband connectivity. Preserving telehealth access using both video and audio-only formats is critical to continued access to health care services.

Properly reimbursed and operable telehealth services are crucial for patient access to palliative care providers across large swathes of rural and frontier Kansas. Further development of secure broadband internet services is also critical for access to care. Indeed, sparse populations, lack of health care workers, and patient inability to travel long distances to access care due to illness severity makes telehealth sometimes the only avenue to offer appropriate palliative support for seriously ill patients in these areas of our state. The advancement of technology allows improved communication, and thus improvement of the experience of telehealth for both professional health care worker and their patients. This allows access to care of otherwise disenfranchised people and can improve the quality of life of individuals with serious chronic illness in a cost-effective way using the current distribution of the workforce in more urban areas.

Access Recommendations

In order to build overall workforce capacity and increase access to quality palliative care within Kansas, we make the following recommendations:

Recommendation 1: Make permanent changes to broaden access to telehealth services.

Strategies:

- Require CMS and private payer reimbursement equivalence between telehealth and in-person visits, addressing both provider and facility payments.
- Continue reimbursement for audio-only services.
- Allow for telehealth access for patients in all service areas, including both urban and rural locations, and allow these visits to occur in patient's home.
- Develop legislation, policies and strategies to support interstate provision of telehealth services.
- Support increase in reliable and secure broadband access for all Kansans.

Recommendation 2: Increase number of certified palliative care clinicians.

Strategies:

- Enhance visibility of a palliative care provider directory on the state website.
- Develop a registrar system to more accurately capture the number and practice locations of certified palliative care clinicians to help guide future training and recruitment efforts.
- Expand the Kansas Bridging Plan (KBP) to encourage palliative care physicians to practice in Kansas upon completion of training.
- Expand the Kansas State Loan Repayment Program (SLRP) to include palliative care professionals (MD, DO, APRN, LCSW) to increase access in federally designated Health Professional Shortage Areas.
- Promote development of incentive programs within health care organizations for professionals including RN, SW and chaplains achieving palliative care certification.
- Promote pediatric palliative care nursing certifications.

Recommendation 3: Enhance reimbursement of the full interdisciplinary palliative care team.

Strategies:

- Educate providers and health care systems on strategies to optimize current billing for high value services such as advance care planning and prolonged care.
- Add palliative care coverage requirement to address reimbursement of non-billing members of the interdisciplinary team including special considerations for pediatrics, adolescents, young adults and perinatal patients.
- Add palliative care coverage requirements as above in all settings (inpatient, home health, community-based, virtual visits) for all public and private insurers without limitation to the number of visits.
- Incorporate palliative care services into covered services for existing state Medicaid waiver programs including Frail Elderly, Physical Disability, and Brain Injury waivers.

- Enhance Dual Special Needs Plans and Managed Long-Term Services and Supports contracts to incorporate advance care planning and symptom assessment into care manager responsibilities.
- Improve state implementation of Medicaid/Children's Health Insurance Program regulations under Section 2303 of the Affordable Care Act which finances concurrent curative and hospice care for children by requiring private/commercial insurers to cover concurrent care.

Recommendation 4: Develop task force to determine feasibility of statewide assessment to understand the magnitude of seriously ill populations for appropriate resource allocation.

Strategies:

- Determine Recommended Minimum Comprehensive Assessment: Pain and symptom distress, Functional status, Cognitive status, Caregiver burden, and social needs, including (but not limited to) financial vulnerability, housing, transportation, nutrition, and safety.
- Determine which provider, settings and interval the assessment will be conducted and how serious illness will be captured in the medical record.
- Develop a registry of children with complex and chronic conditions residing in and receiving treatment in Kansas
- Ensure no person with a serious illness is deprived of regular assessments due to patient age, diagnosis exclusion, payer type, residency category (e.g., skilled nursing care, long term care, foster home, group home, private home, correctional facility).
- Require case coordination and management for all with serious illness regardless of payer or programmatic eligibility.
- Propose specific benefits available to seriously ill Kansans.

Performance Measurements

CAPC Kansas Report Card (Percent of Hospitals with 50 Beds, or More, with Access to Palliative Care.

Baseline: "C" rating

Target: "A" rating

Number of Certified Palliative Medicine Physicians.

Baseline: 21

Target: 30

Number of Certified Palliative Care Advance Practice Nurses.

Baseline: 13

Target: 18

Number of Certified Palliative Care Registered Nurses.

Baseline: 49

Target: 66

Number of Certified Pediatric Palliative Care Registered Nurses.

Baseline: 0

Target: 5

Number of Kansas Counties with Certified Palliative Care Prescribing Providers.

Baseline: 10

Target: 20

Number of Community Palliative Medicine Programs.

Baseline: 13

Target: 20

Number of Kansas Programs Submitting Data to National Palliative Care Quality Collaborative (PCQC) Registry™.

Baseline: 4

Target: 12

Patient Vignette

Mr. Smith was a 62-year-old veteran of the Vietnam War. He was diagnosed with stage IV pancreatic cancer for which he received palliative chemotherapy. He suffered from significant cancer associated pain that was complicated by underlying polysubstance abuse and PTSD, making management of his symptoms challenging. Eventually he required hospitalization when his pain and delirium became severe. He required extremely high doses of pain and anxiety medications to control his symptoms. One night, they assigned a new graduate nurse to his care. Feeling uncomfortable about administering high doses of pain and anxiety medications, the new nurse held these medications, which ultimately resulted in additional distress for the patient. Upon inquiry of the nurse about the decision to hold the medications, the nurse expressed that he felt it unethical to provide these medications, that in doing so he might hasten the patient's death. The nurse had not received proper training to provide adequate pain and symptom management. As a result, not only did the patient experience unnecessary suffering, but it placed the nurse in an uncomfortable position.

As a practicing, certified palliative care nurse practitioner, this is a story that I hear far too often. It illustrates the lack of education and training on palliative care my nurse colleagues receive not only in their undergraduate training but also at the graduate level. I frequently witness the same when working with other providers and clinicians. Palliative care is often seen as the alternative to aggressive medical intervention and thus care is often delayed. Symptoms are often inadequately addressed, and patient and family wishes are not clearly and accurately articulated because the nurse at the bedside or the primary care provider lack the necessary training to skillfully perform these crucial elements of care.

— Janelle Williamson, NP-C, ACHPN

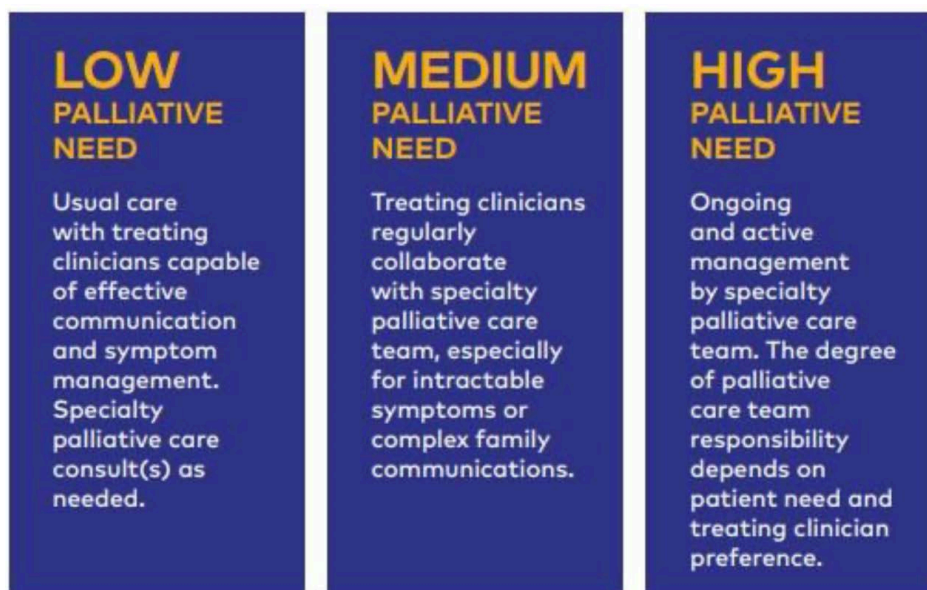
Education & Health Care Workforce Training

Distinction Between Specialty and Primary Palliative Care

Recognizing that the need for palliative care far outweighs the number of specialist palliative care providers, it has given recent attention to the concept of *primary palliative care*. This refers to core knowledge and skills that all clinicians caring for patients with serious illness should have in to order to provide basic pain and symptom management, facilitate patient- centered communication and advance care planning, and coordinate comprehensive care strategies.

Frontline clinicians should have the knowledge and skills to effectively manage anticipated pain and symptom issues, to facilitate advance care planning and goal-concordant care, to work with community support service partners, including hospice, and to provide continuity for their seriously ill patients over time. Referral to specialist palliative care consultants for more complex situations is appropriate. Indeed, the volume of seriously ill patients demands that basic palliative care interventions be delivered by their primary provider teams, with specialist palliative care providers involved based on the complexity of needs, in order to increase overall penetration within the serious illness population.

Outcomes for specialty palliative care have been more comprehensive, with stronger evidence for improvement in the physical symptoms associated with serious illness. However, both specialty and primary palliative care have showed improvements in quality of life, thus showing that primary palliative care plays an important role in the care of these patients. In addition, the provision of primary palliative care from frontline clinicians allows for enhanced continuity in the care of these patients. In this model, the delivery of palliative care is then ideally apportioned between primary, and specialist palliative care providers based on the complexity of needs, as outlined here:



Source: <https://capc.org/blog/palliative-pulse-palliative-pulse-september-2017-palliative-care-comes-of-age/>

Formal Educational Requirements Needed

It is a fact that 100% of patients and families will face serious illness and death. How health care practitioners are trained must strengthen to match and honor this reality.

At present, there are no formal requirements for palliative care training in most post-graduate training programs. Nursing, social work, physician assistant, and chaplain training programs also do not have universal standards for primary palliative care skills or education in their curriculum. Therefore, formal education about palliative care is minimal, leaving practitioners lacking the development of care skills necessary to address the needs of seriously ill patients.

Building the skills of all clinicians who care for those with serious illness is an important strategy to meet the needs of seriously ill Kansans and complement the specialty palliative care workforce.

Unpaid/Informal Caregiver Health Care Workforce

Many people with serious illnesses require an elaborate support system to allow them to function inside and outside the home. Thus, the largest workforce providing care for the chronically, seriously ill, is the informal or unpaid caregiver representing approximately 53 million people according to the 2020 assessment by AARP and the National Alliance for Caregiving. In comparison, this is 10 times larger than the largest professional health workforce in the United States, which is registered nurses.

CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*

43.5 million
2015  **53 million**
2020



18%
2015  **21%**
2020

NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**

More Americans are caring for more than one person.



18%
2015  **24%**
2020

More family caregivers have difficulty coordinating care.

19%
2015  **26%**
2020



More Americans caring for someone with Alzheimer's disease or dementia.



22%
2015  **26%**
2020

More family caregivers report their own health is fair to poor.

17%
2015  **21%**
2020

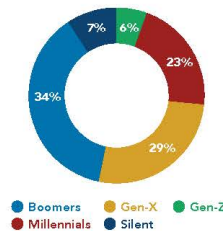


23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?

39%
MEN

61%
WOMEN



45%
HAVE HAD AT LEAST ONE FINANCIAL IMPACT

61%
WORK

AARP

Family Caregiving™

*Provided care to an adult or child with special needs.

**The remainder of this data is based on the 19% or 48 million caregivers caring for an adult.

URL: www.aarp.org/uscaregiving DOI: <https://doi.org/10.26419/ppi.00103.002>

naac
National Alliance for Caregiving

Caregiving in the U.S. 2020,
National Alliance for Caregiving and AARP
For media inquiries, contact Media@aarp.org

For a seriously ill person, unpaid caregivers are those who rise to meet the immediate needs for that person. They may be family, friends or neighbors and they often provide intense and complex care that traditionally is provided by trained professionals. This includes activities such as medication management, wound care, administration of intravenous treatments, interpretation of medical information, management of lines and tubes, and many other functions. This also includes private personal care such as assistance with toileting and exposing themselves to increased personal risk involved with hands on care. Despite these high demands and the significance of their contribution to the overall well-being of patients with serious illness, they often receive very little training or support.

In addition to the unpaid caregiver, a range of community nursing and personal care services are available to a fraction of Kansans limited by programmatic eligibility or payer type. These include the skilled services, such as home health nurses, physical therapists and occupational therapists, but also the less skilled services of personal care attendants, who do everything from showers, personal care, errand running and light housework. While skilled care is often covered by insurance, albeit typically for a limited time, the personal care needs are usually not covered. Medicaid does pay for these services through the Hospital based Home Care services, but these are often limited, and individuals without Medicaid are often unable to pay the large sums of money needed to get appropriate help in the home. For patients whose needs cannot be met in the home, residential care settings such as assisted living and nursing homes provide higher levels of support. However, even in these settings, unpaid caregivers continue to serve as an invisible workforce, providing up to 65 hours of care monthly on average. (Coe, 2022)

The toll on the informal caregiver can be immense as they bear the burden of illness alongside the person they are caring for. In addition to providing intense care to the chronically ill person, the unpaid caregiver often continues to work outside the home and tend to other personal responsibilities. For a large percentage of people there are no solvent avenues for paid personal and medical care in the home daily. Consequently, the unpaid caregiver experiences higher incidence of personal illness, mental health struggles and burnout which often goes unrecognized. For instance, there is a 26% higher incidence of chronic illness/disease amongst caregivers as compared to their non-caregiving peers, with obesity, hypertension and anxiety being the most prevalent.

Providing comprehensive support and building skills for informal caregivers as an essential segment of the palliative care workforce is critical to meeting the seriously ill population needs.

Education & Health Care Workforce Training Recommendations

Recommendation 1: Increase primary palliative care education in the current workforce caring for those with serious illness.

Strategies:

- Require a certain number of palliative care education hours in continuing education requirements for members of the interdisciplinary team (i.e., social workers, chaplains, nurses, and physicians).
- Increase the number and geographic dispersion of attendees at the one-day ELNEC or APRN ELNEC training courses on palliative care for health care professionals.
- Spread the availability of ELNEC training through increased numbers of attendees at two-day ELNEC train the trainer course who can then champion this education within their home regions.
- Evaluate existing education models including EPEC, Vitaltalk, Serious Illness Care Program, and Respecting Choices for feasibility to make available to all appropriate clinicians.
- Negotiate a “frontier” Kansas rate of membership for CAPC and collectively these facilities pay for membership.
- Support passage of PCHETA (Palliative Care and Hospice Education and Training Act) at the federal level.

Recommendation 2: Increase palliative care training in the future workforce caring for those with serious illness.

Strategies:

- Require that all schools of nursing and applicable allied health professional schools, incorporate palliative care and serious illness care into the CORE curriculum of existing program requirements.
- Require that all schools of medicine (i.e., MD and DO) provide both didactic and experiential palliative care curriculum for physician training at both the student level and in the residency programs.
- Provide the opportunity for APRN palliative care fellowship program at teaching institutions within our state.

Recommendation 3: Increase community and home-based support to reduce caregiver burden and enhance their knowledge and skillset in caring for someone with serious illness.

Strategies:

- Support expanded workforce accommodations for caregivers that promote employment retention and allowing for ongoing caregiving.
- Compile free toolkits and resources for informal caregivers on statewide palliative care website.
- Promote training opportunities and resiliency curriculum for informal and paid caregivers
- Establish a Home-based Palliative Care Provider Workforce aligned with CAPC’s Home- based Palliative Care Provider Credentialing Recommendations to relieve caregiver strain.

- Explore avenues for compensation for informal caregivers of seriously ill patients
- Advocate for reimbursement by private and public insurers for travel expenses, including overnight accommodations, related to the care of seriously ill individuals.

Recommendation 4: Improve access to community and home-based services to individuals with serious/chronic illness.

Strategies:

- Advocate for CMS to reduce restrictions of “homebound” services to enhance caregiver support and patient quality of life.
- Broaden eligibility for reimbursement of respite services to include informal caregivers.
- Require consistency in services offered to meet needs which are reimbursed for modernized condition criteria between commercial and public payers.
- Increase access through public and private insurers to hospital-based home care services.
- Advocate for reimbursement and provision of home-based personal care services.
- Create a benefit to access adequately trained respite care providers for unpaid caregivers.

Performance Measures

Number of Professionals Completing One-Day End-of-Life Nursing Education Consortium (ELNEC) Course.

Baseline: 40

Target: 80

Number of Professionals Completing Two-Day Train-the-Trainer ELNEC Course.

Baseline: 10

Target: 20

Number of Advance Practice Nurses Completing One-Day ELNEC Course.

Baseline: 15

Target: 20

Number of Counties with Access to Professional Educational Opportunities in Palliative Care.

Baseline: TBD

Target:

Number of Unique Health Care Providers-Page Views on the KDHE Palliative Care Program Website.

Baseline: 280

Target: 355

Patient Vignette

Lorrie was diagnosed with stage 4 metastatic cervical cancer at the age of 43. The mother of four children, her first thought was for her children. “When I found out the news that I was diagnosed with stage 4 cervical cancer, I was overwhelmed with sadness and fear. I was terrified for the future of my children.”

Further compounding her fears surrounding her cancer diagnosis was the challenge she faced communicating with her providers because Lorrie is deaf. Initially, she attempted communication with her providers using a white board or keyboard but found that this resulted in brief answers and inadequately addressing her concerns regarding her symptoms. She was unable to communicate her fears about what would happen to her children if she did not survive. This left her overwhelmed and confused.

Lorrie was referred to the palliative care team. She found that the palliative care team was willing to sit down and take the time needed to effectively communicate with her using an interpreter. They took the time to help her fully understand her disease, make a treatment plan that aligned with her personal values, and helped her find ways to discuss these things with her children. They found a medication regimen that managed her pain and nausea without causing other side effects and assisted her to change her eating habits to support her goals. They also arranged for a live, ASL interpreter to improve communication with her other care teams. For her, “The palliative medicine team that helped me through my journey made me think positive and to not give up. They are one of the reasons I am still here today.” Four years following her diagnosis, she is in remission and enjoying her family. She remains connected to her palliative care team. If giving advice to other patients with . If giving advice to other patients with serious illness, Lorrie says “Don’t be afraid to ask questions and don’t be afraid to ask for any kind of help. I am fortunate that I got a lot of support from palliative care and am doing a lot better.”

Public & Community Awareness

Community Understanding of Palliative Care

Palliative care first became an ABMS board-recognized specialty in 2008. Despite being over a decade into its official existence, lack of knowledge about palliative care remains widespread within our communities, including even the health care community. In 2011, the Center to Advance Palliative Care performed a public opinion survey that demonstrated only 8% of Americans were knowledgeable or very knowledgeable about palliative care.

In addition to a general lack of knowledge about palliative care, misconceptions remain common and pose a significant barrier to access for those who could benefit from the inclusion of palliative care in their overall treatment. Common misconceptions about palliative care include that it is the same as hospice care, provided only at the end of life, that it will accelerate death, it is only provided in a facility or hospital, and that other treatments need to be stopped in order to receive palliative care (Collins, 2020; McIlfatrick,

2021). In addition, some health care professionals inaccurately assume that patients will have a negative response and/or lose hope if palliative care is discussed, thus refrain from educating their patients on its availability and benefits. However, patients generally report increased satisfaction when palliative care is provided as a part of their overall treatment. In Kansas, according to 2016 BRFSS data, of 72,347 adults who had previously received palliative care, 85% were satisfied with the information they received to control pain, and 82% were satisfied by the emotional support provided.

To increase awareness of palliative care, it is important to consider where patients get their health-related information. Studies have shown that although health care providers are often the most trusted source of information, it is estimated that the health care system is the initial health information source only 15% of the time (Swoboda, 2018). Increasingly, the Internet has become the favored initial source of health information, especially for those with chronic health conditions and those with longer travel times to seek care. However, even some of the most reputable national sources of information for palliative care lack accurate information about palliative care within Kansas. For example, the national palliative care provider directory, getpalliativecare.org, currently lists only three total programs in Kansas, despite the existence of more than this within our state.

In addition, efforts to increase palliative care awareness must be delivered not only on an individual basis, but also with a system level approach in mind. For example, health insurance coverage is a significant determinant of access to health care, including access to palliative care. As health care costs continue to rise, especially for patients with chronic or serious illness, underwriters aim to identify high-cost diseases, use value-based insurance design, and provide focused products that integrate health management strategies such as specific disease management programs to reduce costs for insurers. Palliative care strongly aligns with these cost-savings strategies. Although not the primary aim, quality palliative care reduces direct hospital costs, readmissions, emergency room visits, and unnecessary hospitalizations. Yet often, palliative care remains poorly understood and an underutilized strategy in insurance benefit designs. Thus, targeting education about palliative care to groups that intersect with patients in non-clinical settings is needed.

To enhance palliative care delivery within the state of Kansas, it is then essential to enhance awareness of palliative care, combat prevailing misconceptions, and educate Kansans on how to access services they need.

Health Care Disparities in Palliative Care

According to the 2020 Profile of Older Americans, members of racial or ethnic minorities represented 24% of the total of persons 65 and older. Like the overall population of older adults, this number is expected to grow. However, the racial and ethnic minority populations are projected to grow 115% by 2040 compared to 29% growth for the White (non-Hispanic) population. Given the rapidly growing population of minority adults, especially older adults, the availability of palliative care and quality information that meets the needs of those who will face serious illness is a priority.

Racial and ethnic disparities in health outcomes, access, and quality of care have been well documented. Accordingly, several studies have demonstrated that disparities also exist within palliative care in multiple domains including access, satisfaction,

communication, and in clinical outcomes such as symptom management including inadequate treatment of pain (Johnson, 2013). In addition, care that is received may not be aligned with patient preference as studies demonstrate that racial and ethnic minorities are less knowledgeable about advance directives and have lower degrees of advance directive completion than non-Hispanic Whites (Johnson et. al, 2008, Kwak, 2005).

Mistrust of the health care system due to history of racism in medical research and persistent systemic biases may also decrease utilization and/or provision of palliative care services, leading to unaddressed burdens associated with serious illness.

Health care disparities, especially those that relate to the care of persons with serious illness, exist for other specific populations as well. For example, the lesbian, gay, bisexual, transgender, or queer/questioning (LGBTQ+) community are less likely to have a regular health care provider and are at higher risk for certain types of cancers (Bass, Nagy, 2021). Their partners may also face confusion and challenges in surrogate decision-making selections based on state laws or hospital policies.

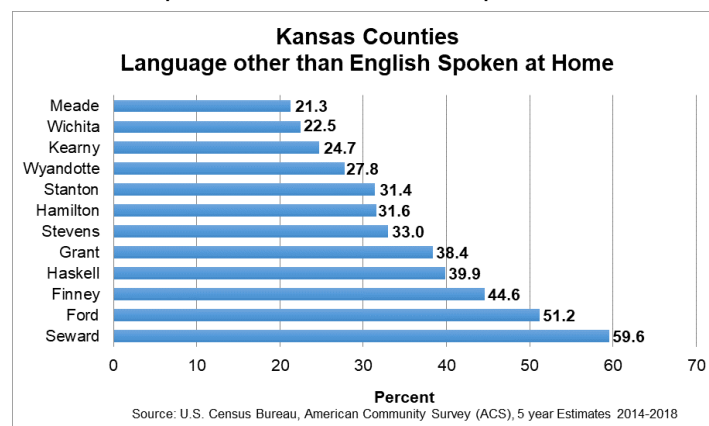
At this time, factors underlying persistent disparities in the use of palliative care remain poorly understood. However, several studies have demonstrated a gap of knowledge about palliative care within these groups, providing a preliminary foundation to direct efforts to combat inequities.

Communication Barriers

Communication is a key component to the delivery of palliative care as well as in the efforts to enhance community awareness. It is well established that language barriers and Limited English Proficiency (LEP) contribute to worse health care quality, poor patient-physician communication, and insufficient physical and symptom assessments. In palliative care, this often results in inadequately treated pain, reduced understanding of diagnosis, prognosis, and treatment options patients and families, and lack of knowledge of available support such as palliative care and hospice care (Silva, 2016).

According to US Census information, in Kansas 12 different counties have over 20% of households that speak a language other than English.

In addition, according to the 2019 Disability & Health U.S. State Profile for Kansas, 6% of all Kansans are either deaf or seriously hard of hearing, representing another significant portion of the population at risk for poor quality of care, health care outcomes and lack of alignment of care with their own preferences. It is also important to consider that the



effectiveness of communication is influenced by health literacy. The Center for Disease Control and Prevention (CDC) defines personal health literacy as “the degree to which individuals have the ability to find, understand and use information and services to inform health-related decisions and actions for themselves and others. “According to recent data from the Kansas Behavioral Risk Factor Surveillance System, 7.5% of respondents had low health literacy which resulted in a seven-fold increase in being unsure of at least one health condition and limited their ability to communicate accurately with their health care providers (Chesser, 2019). Further, the CDC has recently defined organizational health literacy as “the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.” This concept highlights that there is an organizational responsibility to improve health literacy to decrease disparities in care.

Consequently, traditional outreach activities must be modified to consider language and communication barriers as well as health literacy to enhance awareness of palliative care in all segments of our population.

Public & Community Awareness Recommendations

In order to reduce barriers to utilization of palliative care based on a lack of public awareness, we make the following recommendations:

Recommendation 1: Engage and inform Kansans about palliative care with an emphasis on how it is differentiated from hospice and the positive impacts of palliative care at any stage of illness.

Strategies:

- Create and maintain a statewide palliative care website providing accurate information and links to vetted palliative care resources.
- Create a repository of point of service materials that can be easily accessed for use in communities throughout Kansas.
- Encourage national palliative care provider directory participation.
- Capture the attention of the public by providing engaging and accessible products and materials highlighting the needs and benefits of palliative care through communication campaigns.
- Reach a broader state audience through new and strengthened partnerships with both clinical and non-clinical organizations that have overlapping interests in serving the seriously ill patient population (see Appendix).
- Develop and implement in-the-field experiences to provide support to and increase understanding of palliative care, its need and benefits among those in health care and other settings.
- Recommend that the Palliative Care Advisory Council become a permanent state council.
- Collaborate with other state councils to promote representation of palliative care interests in other state plans.

Recommendation 2: Ensure that key palliative care knowledge is integrated into all communities, including the medically underserved, using culturally and linguistically inclusive and appropriate communication principles.

Strategies:

- Create literature tailored to ethnic and racial minorities and medically underserved.
- Make all palliative care brochures and advance directive documents available in both Spanish and English.
- Enable ease of navigation to and translation of state palliative care website to other languages.
- Commit to testing all materials for health literacy, especially for accessibility for those with hearing/vision or other disabilities.
- Provide palliative care information at health care related events in geographic areas with high numbers of minority groups.
- Target counties with high percentages of Language other than English Spoken at Home for palliative care educational events.
- Collaborate with representative organizations and coalitions to assess each community's interests and needs, in order to distribute information and education suited to those needs (See appendix).
- Seek recommendations from representative organizations to offer communication strategies for providers in how to elicit cultural beliefs and address possible issues of mistrust directly and with compassion.
- Educate health care providers on the vital need to utilize professional interpreters during throughout medical care especially during difficult and decision-making discussions as well as importance of non-verbal communication strategies.

Performance Measurements

Number of Providers Listed within the GetPalliativeCare.org Directory.

Baseline: 3

Goal: 10

Number of Unique Views of KDHE Palliative Care Program Website Pages.

Baseline: 120

Target: 150

Number of Annual Downloads and Shares of KDHE Palliative Care Program Website Resources.

Baseline: 250

Target: 400

Relative Search Volume (RSV) of Google Trends/Interest in Palliative Care.

Baseline: 17.5

Target: 20

Social Media Analytics (Click Through Rate) as a Measure of Health Care Engagement with Posts Across KDHE Account Platforms.

Baseline: 0.08%

Target: 0.20%

Communication Campaign Average Monthly Impressions.

Baseline: 132,000

Target: 140,000

Number of Languages Information is Available.

Baseline: 1

Target: 2

Number of Community Events.

Baseline: TBD

Target:

Number of Published Materials Tested for Health Literacy.

Baseline: --

Target: 50%

Provider Vignette

The need for advance care planning has never been as evident as it was during the pandemic. With hospital systems across the state overwhelmed with COVID-19 patients and facing critical nursing shortages, the influx of patients from long-term care and home settings without clearly defined goals further compounded the crisis. Less than 1/3 of Kansans over the age of 18 have advance care documentation in place. Throughout the pandemic, countless families suddenly faced health crises and had never had an opportunity to engage in conversations about what was most important to them as it pertained to their health care. In response, Meadowlark Hospice located in Clay County, decided to sponsor an advance care planning event, "Get your Ducks in a Row." Their director, Amy Burr notes "It is much easier to talk about these things when you aren't in crisis, and it doesn't seem like a threat. This event was set up with a primary goal of being fun to make these hard discussions a little easier and get more people to participate." This free community event was set up in a carnival atmosphere that engaged families in activities that promoted learning about advance care planning and elicited everyone's goals. Of those that attended, 75% completed their advance care planning documents prior to leaving. One participant noted, "We were happy that Meadowlark Hospice took the time and energy to share this very important information with the community. The staff shared their knowledge with us in an engaging way. They really did help us put our ducks in a row! Getting that done took a weight off our shoulders and got us headed where we needed to go."

Emergency Preparedness and Disaster Planning

The challenges of the COVID-19 pandemic have emphasized the need for the integration of palliative care into larger based emergency preparedness and disaster planning for our communities. Palliative care, already resource poor in times of conventional capacity, will be further strained in times of potential mass casualty. However, key components of palliative care including symptom management to relieve suffering, psychosocial support, and specialized communication skills to support decision-making are critical.

Throughout the current pandemic, it has been particularly crucial to ensure that life-sustaining treatments are aligned with patient goals and values to avoid additional suffering and help direct limited resources. High patient volumes and the acuity of severe illness can limit the ability to dedicate adequate time to clarify patient goals of care. Advance care planning (ACP) is based on understanding patient goals, values, and preferences for life sustaining care. In 2014, the Institute of Medicine's report, "Dying in America: Improving Quality and Honoring Individuals Preferences at the End of Life", spurred efforts toward systemic improvements in the provision and completion of advance directives. Since that time, it has been shown that ACP can enhance experiences for patients and families, reduce hospitalizations or unwanted procedures resulting in decreased health care costs, improve overall quality of life and ensure goal-concordant care even in periods of time-critical scenarios. However, most adults do not have advance care planning documents in place. In Kansas, based on 2016 BRFSS data, only an estimated 32.3% have a health care directive or living will.

Aggressive efforts are needed to bring advance care planning and serious illness care planning conversations, across all settings, to scale so that people living with serious illness and/or at risk of serious illness are well informed and are able to express their wishes, values, and treatment preferences should they become seriously ill, whether from COVID-19 or from progression of underlying disease.

The importance of collaboration between skilled nursing facilities, long term care, assisted living, home health and hospice agencies and acute care facilities in provision of care for the seriously ill population in times of limited resources is paramount, however, this is often under- recognized.

Emergency Preparedness and Disaster Planning Recommendations

Recommendation 1: Incorporate palliative care, community-based health care, mental health, social service professionals, and informal caregivers into mass casualty event response planning efforts.

Strategies:

- Nominate palliative care representatives for membership to the Kansas Statewide Health Care Coalition Steering Committee to help inform the Preparedness Program.
- Dedicate section of palliative care website for toolkits and resources such as the CAPC COVID-19 Rapid Response Resource Hub to provide clear guidance for specific communication, symptom management, and other strategies for frontline workers during a public health or mass casualty event.

- Dedicate section of palliative care website for resources to assist with completion of Palliative Care Emergency/Disaster Plans for patients with serious illness or disability and their caregivers. (see appendix)
- Leverage National Preparedness Month to educate the public on the importance of emergency planning for persons with serious illness/disability.

Recommendation 2: Enhance advance directive completion across the State of Kansas.

Strategies:

- Propose statewide standardization of advance care planning documents.
- Recommend and support legislature that would authorize advanced nurse practitioners to complete Do Not Resuscitate (DNR) orders.
- Identify and partner with organizations/stakeholders involved in advance care planning initiatives. (see appendix)
- Provide helpful resources regarding advance care planning on statewide website.
- Leverage National Health Care Decisions Day to educate the public on the importance of advance care planning.
- Pursue dedicated campaign for advance directive completion.
- Evaluate opportunities to increase completion of advance directives at skilled and/or rehabilitation facilities.
- Recommend the provision of incentives through Medicaid for advance care planning completion.

Performance Measurements:

Number of Members Appointed to the Kansas Health Care Coalition Steering Committee with Palliative Care Expertise/Experience.

Baseline: 0

Target: 1

Percent of Kansans Reported to have Completed an Advance Directive from a Behavioral Risk Factor Surveillance System (BRFSS 2021) Interview.

Baseline: 32.7%

Target: 35%

Number of Kansas Clinicians Completing Transportable Physician Orders for Patient Preferences (TPOPP) Training.

Baseline: 138

Target: 159

Number of TPOPP Resource Downloads from www.practicalbioethics.org.

Baseline: 88

Target: 100

Number of Kansas Communities Active in Kansas-Missouri TPOPP Coalition.

Baseline: 17

Target: 20

Number of Order-TPOPP Forms- Page Views Originating from Kansas Internet Protocol (IP Addresses) at www.practicalbioethics.org.

Baseline: 2213

Target: 2545

Number of Wichita Medical Research & Education Foundation Advance Care Directive Document Downloads in

	English	Spanish	Vietnamese
Living Will			
Baseline:	1,600	2,291	151
Target:	1,840	2,635	174
Durable Power of Attorney			
Baseline:	2,200	3,172	128
Target:	2,530	3,648	147
Do Not Resuscitate			
Baseline:	1,500	8,733	114
Target:	1,725	10,000	131
Make the Decision Yours			
Baseline:	2,100	3,172	132
Target:	2,415	3,648	152

Glossary

Behavioral Risk Factor Surveillance System (BRFSS): BRFSS is the nation's premier system of health-related telephone surveys that collect data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. It is designed by the Centers of Disease Control and Prevention.

Center to Advance Palliative Care (CAPC): CAPC is a national organization dedicated to increasing the availability of quality, equitable health care for people living with a serious illness.

Cultural Sensitivity: Cultural sensitivity is an awareness of the ways in which clients' values and perceptions about health care differ from our own.

End-of-Life Nursing Education Consortium (ELNEC): ELNEC is a national and international education initiative to improve palliative care. The project, administered by City of Hope, provides undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students, practicing nurses and other health care professionals.

Evidence-Based Practices: Evidence -Based Practices is the use of systematic decision- making processes or provision of services which have been shown through available scientific evidence to consistently improve measurable patient outcomes.

Health Disparities: Health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.

Health Equity: Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health.

Hospice Care: Hospice care is a program of palliative and supportive care services providing physical, psychological, social, and spiritual care for dying persons, their families, and other loved ones. Hospice services are available in both the home and inpatient settings.

Kansas Department of Health and Environment (KDHE): KDHE is a state agency responsible for Kansas' public health system.

National Palliative Care Research Center (NPCRC): NPCRC is committed to stimulating, developing, and funding research directed at improving care for serious ill

patients and their families.

Palliative Care: Palliative Care is comprehensive, interdisciplinary care for patients living with serious, potentially life-threatening or life-limiting conditions, with the goal of improving quality of life for both the patient and the family. This approach to care prevents and relieves suffering through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Palliative care is delivered based on needs, not prognosis. It is appropriate at any age or any stage of an illness and can be delivered along with curative treatment.

Palliative Care Quality Collaborative: PCQC is a nonprofit membership that supports the only national unified specialty palliative care quality data registry and collaborative. PCQC combines the power of clinical and program data reporting to drive quality and performance improvement in clinical care. Its goal is to improve the quality of care delivered to people with serious illness and the people that support them.

Palliative Care Quality of Life Interdisciplinary Advisory Council (PC-QOL): The 13-member PC-QOL Interdisciplinary Advisory Council was created by legislation in 2018 to develop recommendations and advise the Kansas Department of Health and Environment (KDHE) on matters related to the establishment, maintenance, operation, and outcomes evaluation of palliative care initiatives in the state, and effectiveness of the palliative care consumer and professional information and education program.

Serious Illness: 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 the caregiver.

Telehealth: Telehealth is the use of digital information and communication technologies, such as computers and mobile devices, to access health care service remotely and manage your health care. These may be technologies you use from home or that your doctor uses to improve support health care services.

U. S. Department of Health and Human Services: The Department of Health and Human Services is a federal agency that provides for health and human services and fostering advances in medicine, public health, and social services.

World Health Organization: The United Nations agency that connects nations, partners and people to promote health, keep the world safe and serve the vulnerable - so everyone, everywhere can attain the highest level of health.

Kansas Palliative Care

The Kansas Definition is Informed by Integration of State, National and International Guideposts

2018 Kansas Statute: 65-1,260 (c) Palliative care means an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Center to Advance Palliative Care: Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve 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. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

World Health Organization: Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

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