Country Road:
Bringing Palliative Care to Rural California

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About the Authors
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Palliative care — with its whole-person approach to enhancing the quality of life for patients with advanced illness — has become increasingly available in California over the last decade, resulting in improved patient care and satisfaction, and reduced health care costs. However, most rural communities, which are often medically underserved, offer only limited or no palliative care.1 This is a significant problem because of the state’s immense rural geography, with widely dispersed communities. A 2014 survey found that 22 of the state’s 58 counties have no community-based palliative care (CBPC) services.2

Further, rural communities often lack efficient communication infrastructures, having limited broadband connectivity and capacity, shortages of information technology (IT) personnel, few IT vendors, and restricted IT financing options. These issues severely hamper the ability of communities to adopt innovative health care technologies.7

To better serve rural residents, California expanded Medi-Cal managed care into 28 rural counties in 2012 (Assembly Bill 1467). See Appendix B, a map of California’s 28 rural managed care expansion counties. The expansion extended coverage to low-income families with children associated with CalWORKS, pregnant women, seniors and persons with disabilities, and low-income adults newly eligible for Medi-Cal under the Affordable Care Act (ACA). However, even when adequately insured, rural residents must still contend with the care access issues described above.8

A rural provider may be eligible to become a critical access hospital (CAH)9 or a rural health clinic (RHC).10 Under the ACA, the California State Office of Rural Health administers the Small Rural Hospital Improvement Program, which helps these institutions implement ACA requirements, and the Medicare Rural Hospital Flexibility/Critical Access Hospital Program (FLEX/CAH).11 Flex Program grants are designed to assist rural hospitals with the costs of technical assistance, quality assurance studies, network development, and statewide emergency network support systems.

The Flex Program also helps California’s financially vulnerable rural hospitals obtain CAH designation. Once designated a CAH, a hospital can receive increased revenues through the cost-based reimbursement Medicare program.

The Landscape of Rural Health Care

The expansion of CBPC in rural areas faces challenges common to delivering quality health care of all types in these communities. Independent of geography and topography issues, rural communities have significantly greater numbers of older, sicker, and poorer residents than urban and suburban populations.4 They also contend with high rates of substance abuse and addiction, a problem that is particularly acute in California’s northern counties.5

Many rural counties are designated health professional shortage areas and have a hard time recruiting and retaining staff. Compared to those in urban and suburban locations, rural residents travel farther for care, wait longer for services, and have less access to specialists — and sometimes even to primary care providers. There are also racial disparities in access to care; for example, rural white adults were reported more likely to have a personal health care provider than non-white people.6

Rural California’s health care entities are remarkably diverse in size, scope, and payer arrangements. Some CAHs have only 4 beds; others have the full 25 beds allowed in CAHs. In addition to RHCs, rural communities typically have a mix of public, nonprofit, or community-directed health care services that serve low-income and medically underserved residents. They include community health centers, Federally-Qualified Health Centers (FQHCs), FQHC Look-Alikes, community health clinics, free health clinics, and Indian health clinics.
With limited financial resources and substantial health care provider shortages in rural communities, public health care plans and some commercial plans contract with the ambulatory care delivery system in a complex array of coverage plans and service arrangements.

**Palliative Care Challenges**

In addition to the rural health system’s general challenges, there are particular difficulties associated with establishing and maintaining palliative care in rural communities, despite initiatives to improve the situation (see sidebar below).

**California’s Steps in Supporting Rural Palliative Care**

- In 2012, access to hospital-based palliative care was identified as a quality indicator in the state’s Let's Get Healthy California plan and a critical goal in a subsequent concept paper addressing the health homes program under the ACA (Section 2703) — Health Homes for Patients with Complex Needs.
- Senate Bill 1004, signed into law in 2014, requires the California Department of Health Care Services (DHCS) to establish standards and provide technical assistance to Medi-Cal managed care plans to ensure access to palliative care services for beneficiaries. Medi-Cal managed care plans are expected to begin implementing the law in 2016.
- Palliative care elements were included in California’s renewed Section 1115 Medicaid Waiver, Medi-Cal 2020. A key project in the waiver’s Public Hospital Redesign and Incentives in Medi-Cal (PRIME) is Comprehensive Advanced Illness Planning and Care. The primary project goal is ensuring access to comprehensive care in hospital and community settings — aligned with patient preferences — for all those facing advanced illness.

**Economic Issues**

The experts consulted for this scan cited economics as the most significant barrier to integrating palliative care in rural health care. The challenges they saw included the inability to pay competitive salaries to generalist and specialist providers, underfunded health systems, absence of communication infrastructures necessary to support cutting-edge technologies, and the economic disadvantages of rural communities. Poorer communities have greater difficulty participating in health care options that offer lower-cost means for delivering palliative care, such as telehealth.

The experts saw poverty as a factor that influences a wide range of social determinants of health, including nutrition, education, housing, and the expense of traveling long distances to see health care providers. See sidebar below.

**Young but Not Doing Well**

Some surprising facts were found in the preliminary findings from the Partnership HealthPlan of California’s Partners in Palliative Care pilot (see Appendix C). They found that among rural Medi-Cal participants:

- Many were younger (30s, 40s, 50s) and had much greater psychosocial needs (including the need for housing, transportation, and mental health services) than anticipated.
- They and their referring primary care providers were often reluctant to engage in advance care planning and end-of-life discussions.
- 20% had a diagnosis of cirrhosis, commonly caused by alcohol or viral hepatitis B or C.

These early findings are important, since all Medi-Cal managed care plans will soon be required to ensure that their members have access to palliative care.

They noted further that current and likely future shifts in financing (for example, the Centers for Medicare & Medicaid Services may put CAHs on a prospective payment system) create uncertainty for some payers that might otherwise finance palliative care integration efforts.
Training in Primary Palliative Care

Among the most difficult problems is training sufficient numbers of primary care providers to deliver primary palliative care (PPC), a necessity given the limited supply of palliative care specialists. A 2008 task force appointed by the American Academy of Hospice and Palliative Medicine to study workforce issues found 4,400 hospice and palliative medicine specialists available to fill 4,487 hospice and 10,810 palliative care physician staff positions in current hospice and hospital-based palliative care programs. Primary palliative care is defined as basic skills in physical assessment (pain and symptom management, functional performance status); psychological/psychiatric assessment (depression, anxiety, grief); social assessment (patient’s social role); spiritual assessment (spiritual/existential needs); and communication (family meeting, advance care planning). See Appendix D for a comparison of primary and specialty palliative care, as well as a primary palliative care case example.

A review of the literature on training in primary palliative care in rural areas revealed several informative studies from rural Australia. In one pilot to train primary care providers in palliative care, several challenges were identified: limited knowledge about the field and the skills necessary to practice palliative care, the absence of an interdisciplinary team, inability to provide after-hours access, professional time restraints, limited or no funding for training, and limited access to specialists. Providers also stated that chronic staff shortages and the relatively low number of palliative care patients in their practices further reduced their ability to develop palliative care skills.

In a similar primary palliative care training pilot in Australia, rural providers reported difficulty developing and maintaining ongoing partnerships with palliative care specialists and a lack of clarity within these partnerships about which partner is responsible for coordinating patients, care plans, and communication.

“One of the most important things we can do as palliative care providers is train primary care health professionals in palliative care.” — Karen Ayers, ResolutionCare

“Integrating palliative care in rural communities will require champions at all levels — state and local.” — Lee Kemper, Kemper Consulting Group

Community Engagement

Another frequently cited challenge to establishing palliative care in rural areas is getting buy-in from the community. Experts interviewed for this environmental scan affirmed that rural residents often refuse palliative care when it is offered, confusing it with hospice and end-of-life care. The success of a rural palliative care program, they stated, is contingent not only on quality and cost effectiveness of care, but also on community understanding about what palliative care is, what it is not, and its many benefits. They noted that the process should be done respectfully and creatively through activities like public meetings, one-on-one educational interactions, and workshops. The experts said that palliative care providers will need time and funding to develop relationships and to educate community members about services.

A comprehensive literature review of palliative care in rural settings underscored the importance of community buy-in. The authors said the “community is pivotal to any future plans for developing primary palliative care in the rural area” and that “regardless of the strategies employed, expanding palliative care into rural areas will take explicit planning and unique multicomponent strategies.”

A qualitative ethnographic study of social values in rural palliative care found that initiatives that approached interactions with rural individuals and the community with respect and openness were more likely to be successful. Conversely, initiatives that did not take the time to connect with residents and explain services often found that people shied away from using palliative care because they didn’t understand it.

These findings were further confirmed in a study evaluating an advance care planning model in several largely rural communities in Australia. The authors reported that respecting community values and meeting community members where they congregate (such as libraries, community centers, churches) to discuss palliative care and advance care planning were fundamental to program acceptance and success.
Looking for What Works

Despite the barriers, a number of initiatives have been adding to the body of knowledge about providing palliative care in rural areas and making a difference for patients.

A Learning Collaborative in Minnesota

A novel approach to developing and supporting rural palliative care was tested with 10 communities through the Minnesota Rural Palliative Care Initiative (MRPCI) from 2008 to 2010. The program was created through a partnership between Fairview Health Services’ palliative care program and Stratis Health, an independent nonprofit focused on health care quality.

MRPCI brought together teams of health care providers, including nurses, physicians, social workers, and chaplains in a learning collaborative model. The participants represented hospitals, home care agencies, hospice programs, long term care facilities, clinics, assisted living centers, a college department of nursing, parish nurses, clergy, and public health agencies. MRPCI used the National Quality Forum (NQF) Preferred Practices for Palliative and Hospice Care Quality to help teams establish or strengthen palliative care in rural Minnesota.

“We learned in our rural palliative care program that you have to be collaborative and creative, so we not only engaged community providers, we also brought pharmacists on board and educated them about palliative care.”
— Yvonne Corbeil
Clinical Transformation Specialists

During the project, teams participated in learning sessions and a series of mentoring calls with palliative care specialists. Team action plans based on NQF preferred practices focused on implementing consistent order sets for end-of-life care across care settings, developing advance care planning initiatives, providing clinician education, and building community awareness about palliative care. MRPCI identified the following key lessons learned:

- Secure resources to financially support team time to develop palliative care services.
- Support ongoing networking to ensure sustainability and continued progress.
- Require teams to define their community-based metrics up front (e.g., quantify program impact on costs, quality, hospital admissions, and patient satisfaction).
- Advocate for reimbursement for palliative care services as a covered benefit.
- Ensure that palliative care programs align with local and state efforts to redesign care delivery to maximize efficiency for rural providers.

The initiative highlighted the importance of full and respectful engagement with the community, as well as a multicomponent strategy that is flexible and responsive. Lyn Ceronsky, director of the MRPCI and one of the experts interviewed for this scan, illustrated this approach with the following example: “If a skilled nursing facility needed palliative care, community health care providers might work together to implement a primary palliative care service in the facility that includes facility staff trained in basic pain and symptom management as well as advance care planning.”

Telehealth-Based Outreach

Telehealth is becoming widely used as a way to expand palliative care into rural areas and bring care directly to patients in their homes and communities. The technology is associated with faster and more responsive treatment, the elimination of costly and difficult patient travel, improved communication among providers, and lower health care costs.

In California, telehealth is used by a growing group of health care systems, health plans, and providers (including the Department of Veterans Affairs, Kaiser Permanente, UC Davis Medical Center, and Inland Empire Health Plan). Telehealth tools received a dramatic boost in California with the Telehealth Advancement Act of 2011 (Assembly Bill 415), which removed many of the barriers to providing health services through digital technologies.
The rural health and rural palliative care experts consulted for this survey strongly supported the use of telehealth despite a number of challenges: financing the telecommunications infrastructure, training providers and community residents in the use of different technologies, and securing IT staff to oversee implementation. They noted that the field is expanding at a rapid pace, which will bring greater efficiencies and capacity in the not-too-distant future.

“When we talk about California, we talk about many cultures and languages, so the benefits of telehealth go beyond health. Telehealth promotes communication and cultural sensitivity around death and dying, which is important.”

— Mei Kwong and Mario Gutierrez
Center for Connected Health Policy

Community-Academic Partnerships
Promoting increased access to rural palliative care through community-academic partnerships is another promising strategy. In this model, rural health care providers are paired with palliative care specialists in academic centers for education, training, and mentoring — often facilitated through the use of videoconferencing and other technologies. Such partnerships also provide a mechanism for increasing patient access to palliative care specialists.

Project ECHO (Extension for Community Healthcare Outcomes), developed by the University of New Mexico, is an example. The Palliative Care TeleECHO Clinic model pairs palliative care specialists with primary care providers, primarily in rural areas, via teleconferencing. Through training sessions and case presentations with an interdisciplinary training team, primary care providers emerge with new palliative care skills and competencies, as well as connections with palliative care specialists.

Rural Programs in California
Partnership HealthPlan of California (PHC), a County Organized Health System providing Medi-Cal coverage to more than 500,000 members in 14 Northern California counties, has been conducting a six-month community-based palliative care pilot, Partners in Palliative Care. Launched in late 2015, the pilot findings will inform SB 1004 policy guidelines (see California’s Steps in Supporting Rural Palliative Care, page 4). The project features partnerships with four organizations that have been engaged to deliver palliative care to plan members in four rural counties (see sidebar below). They provide palliative care in members’ homes, over the telephone,

All Stories Are Complex
Every rural palliative care story is different, but typically all are complex and challenging. Mr. Y, a participant in the Partners in Palliative Care pilot, gave us permission to tell his story:

Mr. Y, who is 51, is struggling with end-stage liver disease. He was referred to the palliative care program from hospice after he decided to pursue the option of a liver transplant. A Medi-Cal beneficiary with a history of homelessness, he currently lives with an elderly family member.

Over the five months that Mr. Y has been participating in the Partners in Palliative Care pilot, he has had weekly visits from the program nurse, who monitors his symptoms and coordinates his care with specialists and his primary physician. In addition, the program social worker visits Mr. Y biweekly to provide emotional support and to address his anxiety, advance care planning, and resource needs — including dental services and In-Home Supportive Services (IHSS).*

A month after entering the program, he had a procedure to create a pathway through the liver to connect the portal vein to a hepatic vein, which gave him relief from pain. Two months later he began declining again, with signs of liver failure and recurrence of severe pain. He subsequently underwent a hernia repair. Mr. Y is on the liver transplant list and continues to hope that the surgery will be a possibility for him.

*IHSS helps pays for services to enable elderly, blind, and disabled people to safely remain in their own homes when they are not able to fully care for themselves or handle routine household tasks.
or in one organization’s case, through videoconferencing (see Appendix C for a list of emerging community-based palliative care models in rural California).

At the same time, several rural community-based organizations and health care plans serving rural California residents are delivering palliative care services.

- ResolutionCare in Humboldt County uses videoconferencing and a home-based care approach to provide palliative care to residents wherever they live.

- Inland Empire Health Plan, a Medi-Cal managed care plan serving Riverside and San Bernardino Counties in Southern California, has been providing palliative care to members through a multifaceted strategy that includes clinic-based care and home and community outreach.

While these and other rural palliative care efforts in California are modest, once the Department of Health Care Services (DHCS) finalizes the policy and standards for SB 1004, all California Medi-Cal managed health plans, including those serving rural communities, will be responsible for complying with the law and ensuring access to palliative care services for their members.

Ideas from the Experts

The panel of experts interviewed for this scan agreed that the most viable pathway for integrating palliative care into rural health care is through health plan financing, where aligned fiscal and quality incentives allow for funding of clinical services. Other strategies included palliative care community partnerships, telehealth, and learning and mentoring programs. (Appendix C describes a number of pilots and programs in California.)

The group stressed that both public and commercial plans will need a business case that identifies the benefits of palliative care for participating organizations and patients, as well as cost savings. They pointed to promising models that could be funded through health plans or other sources, suggesting a number of practical partnership models, including:

- Hospital (inpatient/outpatient) and community clinic / health care providers
- Hospice agencies (as the lead partner) with other community supports

The interviewees strongly recommended using community health care workers and other allied health professionals as members of the palliative care team to provide advance care planning education and social service supports.

“So much of the opportunity for spreading palliative care is in education — educating all providers and community health workers.”

― Helen McNeal
CSU Institute for Palliative Care

They also recommended programs that focus on training primary care and allied professionals in palliative care through learning collaboratives and community-academic partnerships such as the MRPCI and TeleECHO models. As an example, they pointed to ResolutionCare, which is leading a six-month Project ECHO-based palliative care training program with eight primary care teams in rural communities in Northern California. The program is funded by the Partnership HealthPlan of California, the California Health Care Foundation, local foundations, and private sources. Director Dr. Michael Fratkin hopes to replicate the model, emphasizing its potential to enhance primary care provider palliative care skills in addressing the complex clinical and social needs of rural residents.

Finally, the experts stressed that efforts to increase access to palliative care in rural California will require three principal things: time to develop programs and relationships with the community, funding for program planning, and quality measures to assess outcomes, program costs, and return on investment.
Appendix A. Interviewed Rural Health Care and Rural Palliative Care Experts

Marilyn Ababio, Director, Advance Health and Hospice Systems Coordinator
Alameda County Health Care Services Agency

Karen Ayers, ACNP, Program Director
ResolutionCare Fund

Lyn Ceronsky, DNP, GNP, CHPCA, FPCN, Nurse Practitioner
Fairview Health Services, Minnesota

Kathy Chorba, Executive Director
California Telehealth Resource Center

Yvonne Corbeil, Senior Project Director
Clinical Transformation Specialists

Michael Fratkin, Executive Director
ResolutionCare

Jeanna Kendrick, Senior Director, Care Management
Inland Empire Health Plan

Mario Gutierrez, MPH, Executive Director
Center for Connected Health Policy

Jill Joseph, MD, PhD, Associate Dean for Research and Professor
Betty Irene Moore School of Nursing, University of California, Davis

Deborah Kelch, MPPA, Director
Kelch Policy Group

Lee Kemper, Founder and Principal
Kemper Consulting Group

Mei Kwong, JD, Senior Policy Associate and Project Director
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Caron Lee, MPH, Improvement Advisor, Quality Improvement Department
Partnership HealthPlan of California

David A. Lindeman, PhD, Director Health Care, CITRIS, University of California
Director, Center for Technology and Aging

Helen McNeal, Executive Director
CSU Institute for Palliative Care

Robert L. Moore, MD, MPH, Chief Medical Officer, Health Services Department
Partnership HealthPlan of California

Devon Neale, MD, Associate Professor, Department of Internal Medicine
University of New Mexico

Karla Weng, MPH, CPHQ, Senior Program Manager, Rural Lead
Stratis Health, Minnesota

Sam Wilburn, Chief, Primary, Rural, and Indian Health Division
California State Office of Rural Health
Appendix B. California’s 28 Rural Managed Care Expansion Counties

Source: Kemper, L., On the Frontier: Medi-Cal Brings Managed Care to California’s Rural Counties, California Health Care Foundation
Appendix C. Emerging Community-Based Palliative Care Models in Rural California

Four of the five models presented in Table B1 are pilot sites participating in Partnership HealthPlan of California’s (PHC) Partners in Palliative Care Pilot. Below are details regarding the pilot service delivery model, payment, and key metrics.

Partners in Palliative Care Pilot (PIPC)

Pilot length. September 2015 to February 2016

Health Plan Member Eligibility

- Life expectancy of about two years or less and not be likely to be cured or to improve
- Likely to or has started to use the hospital or emergency department to manage a late stage of illness
- Patient and family willing to attempt in-home management by a palliative care team
- Declines or is intolerant of further therapy
- Patients in Partnership HealthPlan’s Intensive Outpatient Care Management Program may be eligible if they are not improving
- Dialysis patients would be eligible on a case-by-case basis, dependent on their condition and life expectancy

Payment. A per member per month global payment, which is adjusted up when in-home skilled nursing services are provided. Additional incentives are available for meeting performance targets addressing patient satisfaction, advance care plan (ACP) completion, and utilization outcomes.

Required Services

- Initial assessment
- 24/7 telephone support
- Pain/symptom management
- Advance care planning
- POLST form completion
- Acute management plan
- Caregiver assessment (needs/referrals)
- Warm handoffs from hospital to hospice (hospital health care practitioners introduce patients to a hospice team to facilitate a transition from hospital to hospice care)

Metrics. Program metrics include POLST completion, ACP completion, acute management plan completion, and patient satisfaction. They also include a PIPC Case-Control Study (comparing pilot patients to matched controls), measuring the frequency of ED and hospital admissions, office visits, cost of care, and POLST and ACP completion rates.

Table C1. Current Rural Palliative Care Pilots in California

<table>
<thead>
<tr>
<th>ORGANIZATION TYPE</th>
<th>LOCATION</th>
<th>SERVICE MODEL(S)</th>
<th>STAFFING</th>
<th>PAYMENT</th>
<th>KEY METRICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>ResolutionCare Palliative Care</td>
<td>Eureka, CA Humboldt County</td>
<td>Project ECHO. Six-month training of eight community provider teams in primary palliative care using videoconferencing.</td>
<td>Interdisciplinary team: MD, NP, RN, SW, community outreach worker, chaplain, admin support</td>
<td>Project ECHO. PHC, California Health Care Foundation, donations PPC. Per member per month global payment</td>
<td>See above.</td>
</tr>
<tr>
<td>(RCPC)</td>
<td></td>
<td>PPC Pilot. RCPC approach includes home visits, phone calls, and videoconferencing. Team assists members with accessing technology. RCPC has established community partnerships with local hospitals, clinics, and individual providers.</td>
<td>51 patients in pilot as of 2/29/2016</td>
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</table>
### Table C1. Current Rural Palliative Care Pilots in California, continued

<table>
<thead>
<tr>
<th>ORGANIZATION TYPE</th>
<th>LOCATION</th>
<th>SERVICE MODEL(S)</th>
<th>STAFFING</th>
<th>PAYMENT</th>
<th>KEY METRICS</th>
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<tbody>
<tr>
<td><strong>Collabria Care</strong></td>
<td>Napa, CA</td>
<td>Transitions Palliative Care program (TPC). Case management / clinical support to individuals with serious illness (life expectancy of 12 months or less). There were 163 patients served in 2014. <strong>PPC Pilot.</strong> Napa Valley Hospice Adult Day Services (NVHADS) is implementing the pilot, building off their experience with TPC. With PPC pilot global payment, they are providing more clinical services (RN) and social services. On average, pilot participants receive one home visit each week. The pilot team works closely with primary care providers in the community to refer consultation on pain and symptom management. 20 patients in pilot as of 2/29/2016</td>
<td>RN, SW, medical director of NVHADS, home health aide, volunteers</td>
<td>TPC. Sliding scale, average monthly cost $60 (many pay modest fees)</td>
<td>TCP metrics. See page 11.</td>
</tr>
<tr>
<td><strong>Yolo Hospice</strong></td>
<td>Davis, CA</td>
<td>PPC Pilot. Yolo is new to offering palliative care. PPC pilot leads include an RN and SW. Both work closely with participants’ community primary care providers. For the pilot, Yolo has partnered with Woodland Memorial Hospital/Clinics, long term care facilities, and area palliative care specialists for referrals and patient consultations. 8 patients in pilot as of 2/29/2016</td>
<td>RNs, SWs, hospice medical director (as a community-based program, Yolo Hospice works directly with primary care providers)</td>
<td>PPC. Per member per month global payment</td>
<td>PPC metrics. See page 11.</td>
</tr>
<tr>
<td><strong>Interim HealthCare</strong></td>
<td>Shasta County Tehama County</td>
<td>PPC Pilot. Interim structured their PPC program on their existing palliative care service (program specifics unknown). Interim is working on partnerships with Shasta Community Health Center and other area health care providers. 5 patients in pilot as of 2/29/2016</td>
<td>RNs, SWs (master level), home health aide, physical therapists</td>
<td>PPC. Per member per month global payment</td>
<td>PPC metrics. See page 11.</td>
</tr>
<tr>
<td><strong>Inland Empire Health Plan (IEHP)</strong></td>
<td>Rancho Cucamonga, CA San Bernardino, County Riverside County</td>
<td>Charter Healthcare Group. Contracted with IEHP to provide home-based palliative care to members with end-stage liver/renal disease, and sickle cell — including patients who are homeless. Services focus on pain management, psychosocial support, and goals of care. Landmark. Will be contracted with IEHP to provide care management and medication reconciliation and some palliative care transitions support to IEHP dual eligible members.</td>
<td>MDs, NPs, SWs Landmark. Unknown at this time</td>
<td>IEHP contracts with Charter Health (fee for service). IEHP is contracting with Landmark (under this contract, Landmark will assume financial risk for patients).</td>
<td>Charter metrics: ED admissions Landmark metrics. Unknown at this time.</td>
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### Appendix D. Comparison of Primary Versus Specialty Palliative Care Services and Supports

<table>
<thead>
<tr>
<th>KEY PALLIATIVE CARE SERVICES/SUPPORTS</th>
<th>PRIMARY PALLIATIVE CARE</th>
<th>SPECIALTY PALLIATIVE CARE</th>
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</thead>
<tbody>
<tr>
<td><strong>Physical Assessment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▶ Pain and symptom management</td>
<td>▶ Basic assessment and management of pain and other physical symptoms</td>
<td>▶ Management of complex pain and refractory symptoms</td>
</tr>
<tr>
<td>▶ Functional (performance) status</td>
<td>▶ Basic assessment of functional status, unmet needs at home, and caregiving needs</td>
<td>▶ Team approach to manage unmet functional needs and support families in obtaining supportive services</td>
</tr>
<tr>
<td>▶ Assessment of unmet needs at home</td>
<td></td>
<td></td>
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<tr>
<td>▶ Assessment of caregiving needs</td>
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<td></td>
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<tr>
<td><strong>Psychological/Psychiatric Assessment</strong></td>
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<tr>
<td>▶ Psychological/psychiatric</td>
<td>▶ Basic assessment and management of psychological/psychosocial needs (e.g., depression and anxiety)</td>
<td>▶ Management of refractory psychiatric symptoms</td>
</tr>
<tr>
<td>▶ Assessment of depression and anxiety</td>
<td>▶ Basic assessment of and response to grief/bereavement</td>
<td>▶ More in-depth assessment and discussion of psychological distress</td>
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<tr>
<td>▶ Grief/bereavement assessment</td>
<td></td>
<td></td>
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<tr>
<td>▶ Assessment of fear, grief, and bereavement</td>
<td></td>
<td>▶ Team approach to assessing and addressing fear and grief, and providing support (uses social work and chaplain)</td>
</tr>
<tr>
<td><strong>Social Assessment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▶ Assessment of patient’s social role/ responsibilities, support network, and need for community referrals</td>
<td>▶ Basic assessment of unmet social needs and referral to known community resources</td>
<td>▶ In-depth assessment, and access to more comprehensive social and community resources and referral sources</td>
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<tr>
<td><strong>Spiritual Assessment</strong></td>
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<tr>
<td>▶ Assessment of patient spiritual/existential needs</td>
<td>▶ Discussing spiritual needs and encouraging patients to seek religious or spiritual support</td>
<td>▶ Team approach, including clergy, to support spiritual and existential concerns and identify resources</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
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</table>
| ▶ Patient consult / family meeting   | ▶ Discussing values and goals of care with patients and families:  
▶ Clarifying what is most important  
▶ Helping patients understand choices and consequences  
▶ Coaching patients on working with oncologists or other specialists with conflicting recommendations  
▶ Developing a care plan  
▶ Advance care planning  
▶ Completing code status, Physician Orders for Life-Sustaining Treatment (POLST), or other advance care planning forms  
▶ Identifying proxy decisionmakers  
▶ Referring to community resources for more information | ▶ In-depth discussions:  
▶ Assessing patient and family values and preferences  
▶ Goals of care discussion:  
▶ Quality of life / suffering  
▶ Disease / prognosis / treatment options / implications of treatment  
▶ Code status  
▶ Care plan  
▶ Assistance with conflict resolution regarding goals or methods of treatment:  
▶ Within families  
▶ Between staff and families  
▶ Among treatment teams  
▶ Assistance in addressing cases of near futility  
▶ Completion of advance directive |
| ▶ Goals of care discussions          |                           |                           |
| ▶ Discussing prognosis and treatment options |                     |                           |
| ▶ Discussing options regarding advanced medical therapies such as CPR, mechanical ventilation |                     |                           |
| ▶ Translating values/goals into concrete care plans |                     |                           |
| ▶ Advance care planning              | ▶ Developing patient-centered plans for emergency care and/or end-of-life care  
▶ Introduction and completion of the advance health care directive |                           |
| ▶ Identifying proxy decisionmakers   |                          |                           |
| ▶ Referring to community resources for more information |                     |                           |

Mrs. Williams is a 72-year-old female with diabetes, hypertension, and chronic kidney disease. At her follow-up appointment you ask her about the appointments she missed with the nephrologist. Mrs. Williams expresses concern about the possibility of needing dialysis in the future. She shares that her sister and mother both received dialysis at the end of their lives and that they spent much time in and out of the hospital. She was fearful that the kidney doctor would say she needed dialysis and therefore did not go to her return appointment.

The care of patients with chronic kidney disease (CKD) requires special attention to advance care planning. Primary care providers are able to initiate important conversations about advance care planning early in the disease, before decisions are made regarding initiation of dialysis. As illustrated in this case, primary care providers have the opportunity to learn about patients’ experience of their illness. Ongoing discussions about patients’ goals and fears, as well as education about the progression of CKD, will help to prepare the patient and her family for future consultation with specialists.

Pre-dialysis education should include a discussion of treatment options, including initiating dialysis and the available dialysis modalities, not initiating dialysis and continuing conservative management, a time-limited trial of dialysis, or stopping dialysis with expectation of death. Primary care clinicians can also assist in educating patients about prognosis, both with and without dialysis, and the expected effects of the disease and treatment on function.

The relationship the primary care provider has with the patient’s family can often facilitate the involvement of other family members in advance care planning discussions. Inclusion of family members in these conversations is important. Patients with CKD often find it difficult to initiate conversations with loved ones about preferences. They may choose to extend dialysis due to family pressure or may be unable to make decisions later in the disease course due to cognitive impairment. Surrogates and proxies are then left with difficult decisions without the guidance of the patient’s wishes.

The longstanding relationship primary care clinicians have with patients allows them to be present throughout the course of disease as goals and decisions evolve. Primary care clinicians can also consult palliative care specialists to assist with time-intensive complex decisionmaking regarding goals of care and treatment options, recommendations regarding pain and symptom management, and to help address complicated psychosocial, spiritual, and social issues.

Later in the course of this patient’s illness, a consultation to a palliative care specialist team would be helpful if the patient’s primary physician notes that the patient has had frequent visits to the emergency department, hospital admissions, prolonged hospitalization, a prolonged intensive care unit (ICU) stay, or an ICU stay with poor prognosis.
Endnotes

1. Areas are designated medically underserved by their Index of Medical Underservice (IMU) score. The IMU weights and sums values in four areas: the ratio of primary medical care physicians per 1,000 population, infant mortality rate, percentage of the population with incomes below the poverty level, and percentage of the population age 65 or over.


3. CBPC is defined as palliative care delivered outside of acute care hospitals and independent of enrollment in a hospice program.


9. Some of the requirements for CAH certification include having no more than 25 inpatient beds; maintaining an annual average length of stay of no more than 96 hours for acute inpatient care; offering 24-hour, 7-day-a-week emergency care; and being located in a rural area, at least 35 miles drive away from any other hospital or CAH (fewer in some circumstances).

10. To be classified as a rural health clinic (RHC), the a clinic must employ at least one nurse practitioner (NP) or physician assistant (PA). The NP, PA, or a clinical nurse manager (CNM) must work at the clinic at least 50% of the time the clinic operates. While open they have to furnish routine diagnostic and laboratory services as well as have available drugs necessary for the treatment of emergencies.


15. J. Donald Schumacher, Diane E. Meier, and Hilda Heady, Providing Hospice and Palliative Care in Rural and Frontier Areas, Center to Advance Palliative Care, National Hospice and Palliative Care Organization, and National Rural Health Association, 2005.


21. Assembly Bill No. 415 (2011), accessed January 9, 2016, http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=20120120AB415; The Promise of Telehealth for Hospitals, Health Systems, and Their Communities (Washington, DC: American Hospital Association, 2015), www.aha.org (PDF); “Telehealth Advancement Act,” Center for Connected Health Policy, accessed December 31, 2015, cchpca.org; AB 415 removed limits on where telehealth services can take place, eliminated the ban on email- and telephone-delivered services, and expanded the range of medical professionals who could provide telehealth to include all California-licensed health professionals. It also allowed California hospitals to streamline medical credentialing for telehealth providers. Telehealth in California has support from the California Telehealth Resource Center, the California Telehealth Network, and the Center for Connected Health Policy.

22. “Project ECHO: A Revolution in Medical Education and Care Delivery,” University of New Mexico School of Medicine, accessed January 15, 2016, echo.unm.edu.