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Five Strategies to Expand Palliative Care in Safety-Net Populations

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Clinicians need to reexamine how they care for safety-net populations, especially when such vulnerable patients are living with life-limiting conditions. The authors offer five strategies to develop robust palliative care programs aimed at improving care for these populations: utilizing lay health workers, addressing gaps in care and setting goals of care, creating specialized interventions, shaping the interdisciplinary team for resilience support, and addressing opioids.

When Paul first met the palliative care team, his medical narrative was clear: 40 years old, metastatic lung cancer, a recent myocardial infarction. His disease was incurable.

Then there was the subtext. Time and again, he'd been cited for walking out of hospitals "against medical advice." There was little explanation.

Paul had grown up in poverty, a victim of abuse and circumstance. It wasn't long after marrying his high school sweetheart that Paul experienced what he described as a "slow-motion downward spiral" — substance use, divorce, estrangement from his children. At the time of his diagnosis, he was working odd jobs and living in a hotel. Paul may have "made it out alive," as he once quipped, but he was now dying. Alone.

Before he understood his prognosis — before anyone took the time to review the options with him — Paul underwent aggressive chemotherapy. The complications were severe, including a heart attack. After a prolonged hospital stay left him homeless, his providers delivered the news: "There's nothing more we can do for you." Feeling angry and abandoned, Paul was left with nowhere to go.

Even as his condition worsened, his spirit remained defiant. He refused hospice as "giving up," even though he accepted there was no further curative therapy available. Eventually, he accepted admission into a palliative care program for the most pressing reasons: He had no house, no friends
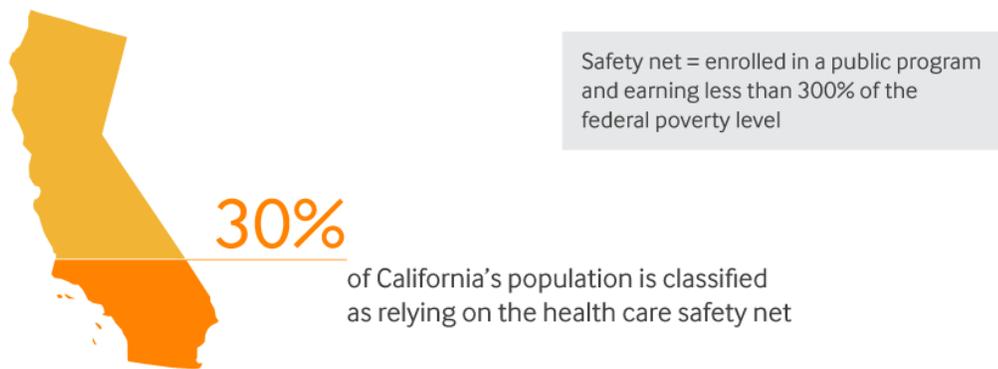
or family, and nowhere to go. The program's willingness to focus on his priority — a place to stay — became the starting point in rebuilding his trust with the medical system.

The Safety Net Often Fails the Most Vulnerable

Paul's medical story may have predicted how he would die, but it said nothing of how he could live with the right support. And sadly, Paul isn't alone in his experience (Figure 1).

FIGURE 1

Millions Rely on the Health Care Safety Net

Safety net = enrolled in a public program and earning less than 300% of the federal poverty level

30% of California's population is classified as relying on the health care safety net

Source: Katrina Connolly, Matthew Newman; "California's Health Care Safety Net: A Sector in Transition," *California Health Care Almanac*, January 2016.

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Paul's story represents the challenges faced by millions of vulnerable Americans who rely on the health care safety net. With a mandate or mission to provide care regardless of ability to pay, safety-net hospitals and clinics across the country serve a substantial share of Medicaid, Dual Eligible, uninsured, undocumented, and vulnerable communities. In California alone, 30% of the total state population is classified as relying on the safety net. That is, they are enrolled in a public program and earning less than 300% of the federal poverty level.[1]p>

> " *Paul's medical story may have predicted how he would die, but it said nothing of how he could live with the right support."*

The safety net serves a substantial swath of low-income communities spanning race, geography, and age. These are people who suffer disproportionately from trauma, behavioral health conditions, and social determinant factors beyond their control, exacerbated by the experience of navigating serious medical illness. And when vulnerable populations confront serious medical illnesses, it's the very factors beyond their control — access to care, social support, health literacy, and financial

resources — that are too often drivers of both quality and cost of care. Lacking agency to advocate, such patients find the care they do receive is often misaligned with their values, needs, and goals.[2]

We profile five strategies to empower palliative care programs to improve care for these populations.

Strategy 1: Utilizing Lay Health Workers

There is a shortage of at least 6,000–18,000 palliative care physicians across the United States, with similar (less quantified) shortages in other palliative disciplines such as advanced practice providers, nurses, chaplains, and social workers.[3, 4] These gaps are only magnified in the safety net, in which specialty services have been historically under-resourced.

Lay health workers (LHWs), navigators, and similar roles provide an important answer to workforce gaps and safety net–specific needs. A 2018 randomized controlled trial at the Veterans Administration Palo Alto Health System paired patients living with stage three and four cancer with specially trained LHWs to focus on advance care planning goals. The longitudinal, relationship-based intervention showed dramatic results: increased patient satisfaction, a fivefold increase in goals-of-care documentation, a doubling of hospice use, and a nearly sixfold reduction in emergency department and hospital use in the last month of life.[5] Similarly, a propensity score matched comparison at the University of Alabama at Birmingham Cancer Community Network found a 7.9% reduction in hospitalizations in patients receiving navigator services, with an associated return on investment of 10:1.[6] While these efforts provide compelling evidence, a critical investment opportunity remains in defining best practice for quality and scaling.

The LHW role addresses three major needs: (1) establishing a trusting, longitudinal relationship with the patient, (2) early development of advance care planning, and (3) resolution of social determinant gaps. Just as medical professionals develop acumen in medical diagnosis and prescribing, those in the LHW role can become experts in "social diagnosis" and "social prescribing."[7] In building trusting relationships in the home setting, a whole-person, whole-environment diagnosis can be generated. Typical issues identified include social isolation, lack of caregiving, food insecurity, and housing risks. Such information often allows teams to address the root causes of recurrent emergency or hospital visits.

Through the LHWs' knowledge and access to community resources, this diagnosis becomes a social prescription in terms of next steps. Hiring LHWs from specific community backgrounds adds population-specific knowledge and credibility. Specific interventions include facilitating involvement of friends and family (if available), advocacy to increase Medicaid-approved caregiving hours based on patient prognosis, outreach to food pantries, and expanded access to housing resources.[8, 9, 10]

A new problem-solving approach develops as a consequence of these processes. The LHW relationship serves as the foundation to discover and resolve underlying unmet needs, which the traditional structures of health care are often ill-equipped to identify and address. And through this

process, a trusting, person-centered dynamic emerges in which basic human needs are addressed as the prerequisite to identifying medical goals and care plans.

Strategy 2: Addressing Gaps in Care and Setting Goals of Care

No single factor defines serious illness care more than patient-specific goals. Typically, goals of care conversations occur episodically, late in illness, emphasize medical treatments over value-based goals, and assume adequate health literacy.[11, 12] These factors are accentuated in safety-net populations, with providers often having limited population-specific awareness and patients (appropriately) prioritizing urgent mental health and social determinant concerns.[13, 14]p> Most Medicaid, Medicare, and uninsured populations have "basic" or "below basic" levels of health literacy, impairing abilities to comprehend and process disease-related decision-making.[15]

> " *Lay health workers (LHWs), navigators, and similar roles provide an important answer to workforce gaps and safety net–specific needs.*"

A useful context to address these gaps combines three strategies: (1) trauma-informed care, (2) motivational interviewing, and (3) video-based decision aids. Childhood trauma correlates with early death and the development of physical and mental illness — a developmental arc more common among vulnerable populations.[16] While medical literature is increasingly recognizing that a serious illness often reactivates prior traumatic experiences, it wasn't until 2018 that we began to see references in literature to integrating trauma-informed care into palliative care.[17, 18]

Although a variety of screening tools can be used, our experience leads us to believe a *universal precautions* approach works best.[19] Therefore, we apply the principles of trauma-informed care to all patients on the assumption of underlying trauma, whether it be from childhood, adult experience, or medical care.[20, 21, 22] While a number of psychotherapeutic treatments exist, in the context of both limited prognosis and resources, the focus is typically on patient experience.[23] The initial clinical perspective shifts from "what's wrong with you?" to "what happened to you?" Specific strategies include: (1) creating an environment of safety by asking patients for permission before asking questions or taking action, (2) active listening, (3) role modeling relational skills (such as showing empathy, respect, and patience), and (4) helping patients consider factors that will improve provider encounters.[24] From an organizational perspective, these approaches must be encouraged by leadership, can be taught in half-day workshops, and are sometimes funded by local foundations.

Through trusting relationships and a trauma-informed perspective, patients can explore deep-seated issues when facing a serious medical illness. Often, this kind of processing involves unearthing unresolved, conflicting perspectives. *Motivational interviewing*, which is a behavioral health counseling style, encourages patients to recognize and resolve underlying conflicts in pursuit of self-identified goals. In goals-of-care discussions with vulnerable populations, these conflicts are often influenced by prior experiences such as discrimination, lack of agency, and feeling misunderstood. As a result, compensatory beliefs develop: Death is equated with disappearance,

hospice is seen as disenfranchisement, and requests for aggressive end-of-life care can be a manifestation of a survivalist mentality.

Motivational interviewing applies four skills to facilitate identifying underlying issues: (1) open-ended questions, (2) affirmations, (3) reflections, and (4) summaries.[25]p> Given the complexities often co-occurring for patients — medical, behavioral health, and social factors — an emphasis is placed on understanding and acknowledging the challenges of daily life. Open-ended questions include, "What is most important to you right now?" and "What would help you the most today?" Affirmations emphasize personhood and resilience, such as, "You want to think about your illness but it's hard when you have so many other things to worry about." Reflections and summaries offer insight to patients by repeating back their words with additional context, "You've been let down in the past, but you don't know how to handle the medical decisions, living alone, and dealing with your symptoms without help." Such approaches create a supportive environment for patients — with input from trusted team members — to see new possibilities.

Finally, the use of video-based decision aids facilitates patient comprehension. Low health literacy presents a major barrier to understanding and processing critical information necessary for medical decision-making. A burgeoning base of evidence suggests that video decision aids may provide vulnerable patients with details and information that are not necessarily communicated in face-to-face verbal discussions with clinicians.[26, 27, 28]

> *Through this [lay health worker] process, a trusting, person-centered dynamic emerges in which basic human needs are addressed as the prerequisite to identifying medical goals and care plans."*

A population-based trial of video-based decision aids in a largely undeserved community led to a nearly 37-point increase (to 39.9% from 3.2%) in POLST documentation (Physician Orders for Life-Sustaining Treatment), a nearly 1-point decrease (to 4.3% from 5.1%) in in-hospital deaths, and a doubling of hospice referral rate.[29] Research shows video aids improve proxy decision-maker accuracy, a critical element in populations for whom friends and family may have low health literacy or be reluctant participants in care decisions.[30]p>

Strategy 3: Creating Specialized Interventions

Specialized solutions may provide critical services outside of the conventional medical system. In Massachusetts, Commonwealth Care Alliance (CCA) — a not-for-profit, community-based health care organization that serves more than 32,000 members who are dually eligible for MassHealth (Medicaid) and Medicare with complex medical, behavioral health, and social needs, including those with disabilities — has pioneered two strategies in this spirit.

First, knowing that patients with serious medical illness do not want to leave the trusting relationships established in its home-visiting primary care program, CCA partnered with a local hospice to provide *a la carte* services. That is, when patients refuse hospice admission due to fears

of losing access to their CCA team or acute care options, a flexible benefit structure facilitates new options.

In the a la carte model, CCA remains the main care system and pays for all inpatient, medication, durable medical equipment (DME), personal care attendants, and other medical expenses. The hospice benefits from longer engagement periods, with less paperwork burden and a lack of DME and medical costs. Patients benefit by maintaining their CCA relationships but using the hospice services, on a fee-for-service basis, for specialized end-of-life care needs such as nursing, social work, physical and occupational therapy, chaplaincy, and 24-7 coverage.

At all times, patients are free to instead choose the traditional Medicare Hospice Benefit (MHB), which would require transition to the hospice team for subsequent medical care. Barriers to the success of this a la carte model include discomfort among hospice providers unused to a co-management role definition, with its attendant changes in staffing, contracting, and billing for specific services instead of the usual bundled per diem payment of the MHB. In the most recent 18-month look back, internal CCA data showed an average total savings of $3,174 per patient over the final 6 months of life has occurred.

A second CCA strategy involves InstED, a specialized community paramedicine service.[31] In 2014, CCA spearheaded a pilot in Massachusetts to repurpose acute care paramedics to *treat in place* rather than require transfer to the ED for evaluation. In-home palliative paramedicine interventions include rapid IV treatment of seizures, dyspnea, and pain. Social supports include responding to patient or family anxiety, repositioning problems, falls, and caregiver support. Critical professional issues include the requirement for an expanded paramedic scope of practice, associated training, and the development of refined clinical protocols in partnership with CCA physicians.

> *Although a variety of screening tools can be used, our experience leads us to believe a universal precautions approach works best."*

In the program's first year, 81% of paramedic home visits ended up with the patient able to remain at home (allowing for home-based primary care follow up in the subsequent days). When program costs were compared to reductions in acute care use for patients who did not need transfer, a third-party analysis found substantial savings. Non-diverted patients showed per patient-episode savings at $791 at 7 days, $3,677 at 15 days, and $538 at 30 days after the initial paramedic visit.[32]

Strategy 4: Shaping the Interdisciplinary Team for Resilience Support

Clinicians working with patients in the most difficult social and psychological circumstances are at particularly high risk for burnout.[33] Both research and experience inform our belief that developing an expanded team practice model not only helps mitigate these pressures, but also facilitates processing the emotional labor of repeated distressing patient care experiences in ways that build resilience.[34, 35]

Conversely, if staff believe they are helpless in the face of patient suffering, moral distress follows.[36] In safety net–focused programs, the collective existential suffering and life circumstances of patients tests the most resilient clinicians. What is an exceptional situation in conventional palliative care becomes commonplace. To help, an expanded use of palliative care language and framing facilitates the ability to see ambiguous or even traumatic outcomes in meaningful ways. Such examples include:

1. **Patient-defined dignity.** The patient discovers and defines his or her values, which may include remaining homeless, living in unsafe caregiving situations, or pursuing aggressive measures until the last moment as part of a "survivor" mentality.[37]

2. **Non-abandonment.** Unless staff safety becomes an issue, patients' ambivalence or indifference to care is viewed primarily as a response to disenfranchisement, discrimination, and life trauma.[38]

3. **Bearing witness.** Providing attention without judgment becomes a singular intervention, especially when patients acknowledge difficult past actions or regrets.[39]

4. **Professional boundaries.** Safety-net palliative care combines empathic clinicians with exceptionally complex patient needs. To retain healthy boundaries, a useful framework distinguishes fixing from serving. Fixing assumes something is broken and needs repair. But serving sees the person as whole (and as an equal) but benefiting from support.[40]

Quadruple Aim goals extend beyond the classic triad of patient experience, quality, and cost to prioritize the work life of providers and staff.[41] Especially in safety-net palliative care, staff care drives patient care. Team leadership reinforces self-care group norms in the form of recognition (effort over outcome), spirituality (especially for vicarious trauma experienced by staff), ritual, work flexibility, and team parity.[42, 43] Case review is led through a dual lens of problem solving for patients while providing support for involved staff. Such support for processing difficult experiences is framed through the use of expanded language (such as dignity, harm reduction, and boundaries) that helps clinicians regain perspective and a sense of meaning from their work.

> *Through trusting relationships and a trauma-informed perspective, patients can explore deep-seated issues when facing a serious medical illness."*

Necessary leadership and staff qualities include comfort with ambiguity, embracing the challenge of new problems, and a commitment to continuous learning. Ideal prior work experiences include hospice, home health, homeless clinics, and behavioral health settings. Medicaid managed care case management experience can provide unique insights into navigating social service and behavioral health resources. Essential personal traits include empathy, comfort with underserved home visit settings, coordination and communication skills, and a team-based orientation. Palliative care skills can be taught assuming these personal traits. However, in our experience,

a palliative care work background does not automatically translate into the personal qualities required for this patient population and these settings. Use of behavioral interviewing strategies, an emphasis on prior safety-net delivery system experience, and a realistic description of daily work (including ride-alongs) facilitate hiring best-fit team members.

Strategy 5: Addressing Opioids

Finally, given the opioid epidemic and the higher prevalence of substance use disorders (SUDs) in safety-net populations, no care model discussion would be complete without addressing opioids. While comprehensive strategies for safe opioid use in hospice and palliative care exist,[44] they may not account for the scale and complexity of risk associated with safety net–focused work.

At its most extreme, a two-tiered approach to high-risk patients living with serious illness is applied. Despite significant physical pain related to medical illness, use of opioids is minimized among safety-net patient populations due to concerns about SUDs, but opioids are then much more freely prescribed without appropriate safeguards once a patient transitions into hospice care. The former scenario creates needless suffering and disenfranchisement. In the latter situation, overdose and diversion can occur without appropriate oversight. We believe a more population-specific approach, independent of program enrollment, achieves greater safety and patient care goals.

Key observations include clinician implicit bias and assumptions about the legitimacy of pain complaints in this population, pain as a multifaceted experience and risk, and staff anxieties related to opioid prescribing. Opioid use presents a continuum of risk across populations and care settings. Clinicians are often surprised when elderly patients harbor substance use problems.[45] Conversely, we have seen formerly homeless patients with intense substance use histories manage opioids at end of life with remarkable discipline.

> " *In safety net–focused programs, the collective existential suffering and life circumstances of patients tests the most resilient clinicians."*

While opioid *universal precautions* promote awareness across population groups, using assessment tools (like the Opioid Risk Tool) — which are not validated in palliative care settings and often place people with a prior SUD history in the highest risk group — may not adequately stratify ongoing risks. We believe a nuanced approach — using a relationship-based, multifaceted assessment of risk — best promotes safety and patient trust. Such strategies include:

5. Conducting a differential diagnosis of uncontrolled pain, including considerations of progression of disease, pseudo-addiction, chemical coping, existential pain, tolerance, and recurrent SUD.[46]

6. Using lock boxes, providing small amounts (1- or 2-day supplies), limiting dosages, and using urine drug screens to mitigate risk (even in very poor prognosis situations).

7. Understanding that the ability to provide opioids safely in high-risk situations is often limited by staffing bandwidth as much as patient factors, so adequately resourcing staff support for such intensive care needs should be a proactive decision whenever possible.

8. Supporting staff psychological needs when patients make distressing decisions, such as choosing to endure physical pain at home (rather than enter a facility where opioids can be administered safely.)

Revisiting Paul

As it turns out, Paul wasn't "noncompliant." He was scared.

He didn't walk out "against medical advice." He walked out because he had suffered abuse by a man when he was just a child. A male nurse entering a dark hospital room was enough to trigger those painful memories.

Paul was never a "problem patient." He was simply a patient. One who deserved to be treated as wholly human, particularly during the heartache of serious illness.

Like millions of Americans, Paul could easily have died the way he lived: disenfranchised, isolated, and neglected. Instead, he died peacefully in supportive housing and surrounded by providers he trusted. As his life came to an end, he remarked of his care, "I used to be falling, and now I am not."

As health care providers, we're called to heal. And healing Pauls is one of the greatest moral and financial responsibilities in health care. It's also achievable.

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Acknowledgments

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