The Cambia Sojourns Scholars Leadership Program: Project Summaries from the Inaugural Scholar Cohort

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Abstract

Background: As palliative care grows and evolves, robust programs to train and develop the next generation of leaders are needed. Continued integration of palliative care into the fabric of usual health care requires leaders who are prepared to develop novel programs, think creatively about integration into the current health care environment, and focus on sustainability of efforts. Such leadership development initiatives must prepare leaders in clinical, research, and education realms to ensure that palliative care matures and evolves in diverse ways.

Methods: The Cambia Health Foundation designed the Sojourns Scholar Leadership Program to facilitate leadership development among budding palliative care leaders.

Results: The background, aims, and results to date of each of the projects from the scholars of the inaugural cohort are presented.

Introduction

Development of new leaders across clinical, quality, education, and research areas is important for the growth of palliative care. A report on the impact of the pioneer leadership program, the Project on Death in America (PDIA) Faculty Scholars, demonstrated the value of nurturing new leaders to influence the research, program development, and policy landscape of the field.1 Since the PDIA granting period ended in 2003, the field has grown exponentially, with almost 150% expansion of clinical services,2 proliferation of accredited training programs, and a rapid growth of the evidence base.3 Calls for further growth are continuous, as the field’s philosophy of a patient- and relationship-centered approach to living with serious illness is increasingly viewed as vital for organizations seeking to meet goals related to quality and cost in their sickest patients. Leading, managing, and sustaining this continued growth requires cultivating cohorts of leaders who are prepared to respond to shifting demands as the field matures and evolves.

The Cambia Health Foundation Sojourns Scholar Leadership Program is an initiative designed to identify, cultivate, and advance the next generation of palliative care leaders. The program supports outstanding emerging faculty and clinicians by investing in their professional development. Sojourn Scholars receive a 2-year grant to conduct an innovative and impactful clinical, research, education or policy project in the field of palliative care, and develop a leadership career plan. In addition, national and local leaders mentor the Sojourn Scholars, further broadening their learning and leadership development opportunities.

Since its inception in 2014, the Sojourns Scholars program has awarded $3.6 million in grants to 20 scholars across the nation. The program is part of the Cambia Health Foundation’s overall commitment to improve access to, and quality of, palliative care; facilitate an open dialogue about end-of-life issues; strengthen the workforce to meet increased consumer demand; and recognize leadership, innovation, and inspiration in palliative care.

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Herein we summarize the leadership projects of the inaugural cohort of Sojourns Scholars, focusing on the background, approach, and early results. Descriptions of the projects are meant to invite conversation and collaboration regarding the leadership projects, and demonstrate early lessons learned in performing such initiatives in busy and complex environments.

**Integrating Multidisciplinary Palliative Care into the Intensive Care Unit (IMPACT-ICU): Disseminating a Palliative Care Education and Quality Improvement Initiative for Bedside Nurses—Wendy G. Anderson**

Research is increasingly demonstrating the value of palliative care integration into intensive care units (ICUs) for patients and families, including support, symptom management, and communication about prognosis and goals of care. Sustained integration of palliative care into the ICU requires involvement of nurses as patients’ closest bedside provider. Lack of education is a key barrier to nurses’ participation in palliative care discussions. Integrating Multidisciplinary Palliative Care into the Intensive Care Unit (IMPACT-ICU) is a quality improvement program designed to integrate palliative care into the ICU by training and supporting bedside nurses. The program positions bedside nurses to coordinate primary palliative care, including symptom management, family support, and communication about prognosis & goals of care. IMPACT-ICU was developed by an interdisciplinary and multispecialty team at the University of California, San Francisco (UCSF) Medical Center in 2011, in response to requests from critical care nurses for training in communication and increased specialty palliative care support in the ICU. It was refined at UCSF between 2011–2013, and was disseminated across the five University of California Medical Centers between March 2013 to August 2015. The focus of this Sojourns project is to make the IMPACT-ICU program accessible to nurses working in other hospitals and health systems.

IMPACT-ICU has two main components. The first is an 8-hour learner-centered workshop that trains nurses to facilitate communication about prognosis, goals of care, and palliative care among families and physicians. This workshop is taught by a multidisciplinary team of experts in palliative care, critical care, and communication. In role-plays, nurses practice conversations with families, physicians, and in family meetings. A reflection session teaches self-care practices to address nurses’ distress and burnout. The second component is proactive specialty palliative nursing support for ICU bedside nurses. Palliative care advanced practice nurses and nurse educators round regularly at the bedside to coach bedside nurses through the process of screening for and developing a plan to address palliative care needs; they are available for consultation at other times. Palliative care consultation services assist the ICU care team for complicated cases. The objective of this Sojourns work is to disseminate IMPACT-ICU to other hospitals and health systems.

For the University of California Health implementation of IMPACT-ICU, we designed a train-the-trainer program, focused on small group role play facilitation skills for communication training. Twelve nurse leaders across the five centers completed this train-the-trainer program. These leaders then implemented communication workshops and proactive specialty palliative nursing support at their centers, training a total of 527 nurses as of January 2015. In our Sojourns-supported work to date, we trained 9 leaders from 3 centers in California, including a community hospital system and a program that has adapted the program for acute care nurses. These leaders are in the process of implementing programs for bedside nurses at their centers. IMPACT-ICU has highlighted the important role that palliative care services play not only in providing direct specialty palliative care to patients, but also in educating and supporting frontline clinicians. In working closely with programs and hospitals who are interested in establishing the IMPACT-ICU program at their institutions, it has become apparent that the in-person train-the-trainer session model is not feasible for many institutions. Thus, we are working to develop on-line resources through which nurses at any center could access the fundamentals of our curriculum.

**The Big Picture Project—Renee D. Boss**

Modern neonatal care is impressive—many infants survive and thrive due to intensive care, surgeries, and other interventions. Yet as intensive care is employed for infants with ever more tenuous conditions, these technologies also generate survivors dependent on mechanical ventilation, intravenous nutrition, or even ventricular assist devices.

Chronic critical illness occurs in approximately 5%–10% of adults with respiratory failure, with its constellation of neuroendocrine abnormalities, recurrent infections, poor nutrition, and brain dysfunction. While prevalence estimates for infants are not available, chronic critical illness probably occurs in as many as 30% of patients in the neonatal ICU. In one study, 1% of pediatric ICU patients accounted for 18% of ICU bed days, and more than 70% of survivors had poor to very poor outcomes. Chronic critical illness is, in fact, much more predictable for pediatric than adult ICU patients—only a few adults who have surgery will be hospitalized for months, but most infants with complex congenital heart disease will be hospitalized for months.

Systems of medical decision-making, and clinician training to guide families, have not kept pace with the coordinated longitudinal care needs of these infants. ICU models for staffing and workflow prioritize quick stabilization and patient turnover. When these models shape the care of infants hospitalized for months, daily decision-making is easily fractured from the big picture, or overall goals of care. Infants with additive complications exceed the capacity of medical evidence about risks, benefits, and prognosis. Their families face ongoing decisions about whether new interventions should be tried, such as tracheostomy and long-term ventilation, so that the infant can leave the ICU.

Based on relevant work with chronically critically ill adults, and on informative data from our own work in the neonatal ICU, we designed a three-pronged intervention aimed at enhancing communication and decision making for chronically critically ill infants and their families. The Big Picture Project targets families, clinicians who guide discussions with families, and systems of decision making for these infants.

The family intervention comprises tools to prepare families for longitudinal communication in the neonatal ICU. It includes informational videos and brochures that help families understand the flow of information and decision-making
within the medical team, and between the medical team and the family, during a neonatal ICU stay. It also includes a Question Prompt List for families, available on paper or electronically, with components targeted at evolving and prolonged hospitalizations.

The clinician intervention is an adaptation of our Neonatal Critical Care Communication (NC3)\textsuperscript{15} communication skills intervention; we have adapted NC3 for interdisciplinary clinicians (neonatal ICU, pediatric ICU, pediatric cardiology) who collaborate longitudinally in caring for infants with complex congenital heart disease. We will conduct several 1.5-day trainings as well as recurrent booster sessions for clinicians at Johns Hopkins School of Medicine.

Finally, the ICU system intervention aims to first describe the baseline system of longitudinal medical team and family decision-making for chronically critically ill infants with congenital heart disease. This analysis will inform the development of a tool for documenting/tracking and analyzing this system of decision making. This tool will allow us to examine the impact of interventions on team communication, coordination and decision making in this population.

Our next step will be to use the data regarding family, clinician, and system interventions to directly inform a multicenter study that will expand these interventions to all infants whose ICU hospital stays are expected to be in excess of 30 days.

**Palliative Care Research Proposal: The Dementia Symptom Management at Home (DSM-H) Program en Español—Abraham A. Brody**

With the passage of the National Alzheimer’s Planning Act in 2010, and the implementation of the National Alzheimer’s Plan, the United States has recognized that we are in the beginnings of what will become a significant public health and economic emergency.\textsuperscript{16} The health care costs of dementia, estimated at $226 billion per year, are already greater than the cost of cancer and cardiovascular disease combined.\textsuperscript{17} The symptoms of Alzheimer’s disease and related disorders cause significant burdens on both persons living with dementia and families, and are a major focus of the National Alzheimer’s Plan. Of major concern to both is ensuring adequate treatment of pain and neuropsychiatric symptoms such as aggression, delusions, hallucinations, and wandering.\textsuperscript{18,19} Moreover, there are significant disparities in treating this population.\textsuperscript{20,21} Given access, cultural, and other barriers, persons with dementia of Hispanic descent often receive poorer care and have greater incidence of pain and neuropsychiatric symptoms.

While Alzheimer’s disease centers and other specialized memory clinics can provide outstanding evidence-based care, they are often difficult to access, especially for minority populations.\textsuperscript{22} One widespread form of care in the United States that already provides care to these patients is home health care. Over 12,000 home health care agencies provide care to more than 4.7 million patients annually,\textsuperscript{23} of whom 30% are estimated to have some form of cognitive impairment.\textsuperscript{24} However, little research has been performed in providing interprofessional patient- and family-centered care in home health, and even less on the needs of persons with dementia and their caregivers. Because this population widely utilizes home health care, yet home health care agencies are unequipped to manage symptoms in persons living with dementia, we developed the Dementia Symptom Management at Home Program (DSM-H) to improve the quality of life of these patients and their caregivers.

The DSM-H is a multicomponent, evidence based behavioral intervention that provides: (1) online, interactive training modules to nurses and physical and occupational therapists on identifying dementia, assessing and managing pain and symptoms, communicating as a team, and communicating with the caregiver; (2) a mentorship model in which dementia champions are trained and serve as resources within the agency; (3) treatment algorithms for neuropsychiatric symptoms, interprofessional care plans, validated assessment instruments, and caregiver teaching sheets. For the DSM-H en Español, we provided culturally appropriate translation of caregiver teaching sheets, as well as information to home health clinicians on the cultural differences that may affect care in this population.

We are currently in the implementation phase of performing a cluster-randomized controlled trial of the DSM-H and DSM-H en Español in a large, nonprofit home health care agency serving the Bronx, New York, a highly diverse county with the poorest health in New York State.\textsuperscript{25} Four care teams are receiving the intervention and three are serving as controls. The aims are to examine the effect of the DSM-H (Funded separately through The Robert Wood Johnson Foundation) and the DSM-H en Español on pain, symptoms, and caregiver-rated quality of life; caregiver burden and depression; and hospital readmission and emergency department visits. Recruitment of 150 patient–family caregiver dyads has begun, and will be measuring outcomes will measure at baseline, 15, 30, and 60 days.

Our primary lessons learned to date, given that recruitment is just starting, have focused on how to implement a complex intervention in the home health care setting. There are significant new pressures on home health agencies, including the effects of quality reporting, bundled payments, and accountable care organizations that have caused significant changes in how agencies work. This has increased the necessity of developing and cultivating a coalition at the agency, not just a single point of contact, which has taken time, and endured leadership turnover. Partnership development has included care teams, information technology, intake, and quality. A coordinated and thoughtful approach that limits burden to all of these groups has been required to move this complex project forward given these pressures. We hope to use the data and implementation lessons learned from this pilot to move forward with a multisite trial to test its efficacy in diverse settings, and then disseminate nationwide.

**Best Case/Worst Case: A Communication Tool to Assist Older Adults Facing Difficult Surgical Decisions—Toby C. Campbell**

Surgery frequently burdens frail older patients with aggressive treatments they do not want\textsuperscript{26} and that have a limited ability to prolong life or return these individuals to a pre-morbid quality of life.\textsuperscript{27,28} Operations performed on older adults with chronic illness are increasing\textsuperscript{29} such that 25% of older Americans undergo a surgical procedure within the last 3 months of their lives.\textsuperscript{30} Because frail elderly patients are more likely to require intensive care and prolonged
hospitalization, a decision to proceed with surgery can start a patient along a path of escalating commitment to aggressive therapy that may be inconsistent with their personal preferences. Because surgeons would prefer not to operate on patients who would want to limit aggressive postoperative intervention, and patients who are fully informed about the limitations of returning them to a fully functional life may choose to avoid surgery, there is a critical opportunity to intervene at the point a decision is being made. This intervention, a communication tool called Best Case/Worst Case (BCWC), was designed to meet the needs proposed by Elwyn et al., for in-the-moment assistance with high-risk decisions. The intent is to improve the quality of shared decision-making conversations between patients, their families, and their surgeons so that the clinical inertia seen after a decision to have surgery can be carefully considered before the operating room. BCWC structures the decision-making conversation between surgeons and patients by clearly narrating the range of possible outcomes between two options and provides the patient with a simple graphic aid, created in the moment, with pen and paper.

We enrolled 29 attending acute care surgeons into the study and 25 completed training to use the BCWC tool. We have screened 89 patient/caregiver dyads, consented 33, and enrolled 32 to date with 12 in the standard care group and 20 in the intervention group. The training program was developed and refined to fit a 2-hour training session which could accommodate 1–3 surgeons per session. Our qualitative and quantitative methods will characterize the ability for surgeons to incorporate the use of the tool into their regular practice as well as patient’s ability to use the discussion and the paper tool to inform their medical decision-making.

In the project to date, we have seen that many surgeons can learn to use the tool effectively with a single training session, though most require additional real-time coaching to fully adopt the strategy. The surgeon’s response to the tool is almost uniformly positive with the vast majority reporting the tool is easy to use, is better than their current counseling of patients, and is a reliable method for helping patients make decisions. Patients and families also respond very favorably to the tool and report that it continues to be helpful for them even after the acute event. As one patient expressed, “What the particular risks were for you and he had a very nice little piece of paper, which we still have, that explained the worst case scenario, the best case scenario. And that’s nice to refer back to now at this point.”

We have refined our training approach and are developing online teaching modules to deliver key content components as interest builds from other sites to use the tool in clinical care and clinical trials. We will test the revised strategies with resident surgeons as we make plans for subsequent funding for further efficacy trials and dissemination of the BCWC tool.

Severe Acute Brain Injury: Identifying Palliative Care Needs in the Neuro-ICU—Claire J. Creutzfeldt

Severe acute brain injury kills 12 million people annually and is the leading cause of disability worldwide. This group of diseases includes stroke, traumatic, and hypoxic–ischemic brain injury, each of which has a high mortality and can leave survivors in a state that some consider “worse than death.” These neurologic catastrophes share a unique illness trajectory that requires a highly coordinated, interprofessional approach and is distinct from other chronic illnesses such as heart failure, cancer, or dementia. On presentation to the emergency department, patients with severe acute brain injury depend on aggressive life-sustaining treatment including intubation and mechanical ventilation, neurosurgery, and artificial nutrition and hydration to survive. These treatment decisions have to be made early on, when long-term prognosis is uncertain, when the patient is unable to communicate meaningfully, and when the family members are actively grieving, looking for guidance from physicians they have not met before, and trying to determine what their loved one would want.

The palliative care needs for these neurologically critically ill patients and their families are substantial yet have received little attention. Given the acuity in which these patients present, several important palliative care aspects inevitably fall to the neuro-ICU provider as the primary palliative care provider. Palliative care specialists are consulted for some patients but guidance is lacking regarding indication or ideal timing for PC consultation. Our goal is to learn more about the palliative care needs specific to severe acute brain injury. The results of our project will form the basis of an educational tool for primary and specialist palliative care providers who care for patients with severe acute brain injury and their families.

We have used a combination of quantitative and qualitative research methods (a “mixed methods” approach) to evaluate the characteristics and the burden of palliative care needs in patients with severe acute brain injury. We started a quality improvement project in our neuro-ICU using a palliative care needs checklist. Every day at the end of the discussion of each patient, the medical team reviews four questions: (1) Does this patient have any pain or distressing symptoms?; (2) Does the patient or family need social support or help with coping?; (3) Have we addressed patient/family concerns about prognosis?; and (4) Do we need to (re-)address goals of care or adjust treatment according to patient-centered goals? Daily use of an earlier version of this checklist was associated with more family conferences (p = 0.019) and a trend toward more palliative care consultations (p = 0.056). Our results suggest that such a checklist increases the clinical team’s awareness about potential palliative care needs of patients or family and ensures that a daily conversation takes place among neuro-ICU clinicians about every patient’s palliative care issues.

Other research projects include a large retrospective cohort study to evaluate the prevalence of previously published palliative care consultation triggers in the neuro-ICU. Using the project IMPACT database, we found that the overall proportion of patients meeting triggers was not significantly different in neurologically critically ill compared with medically or surgically critically ill patients (15.8% versus 13.9%), but that different types of triggers were being met. Among those meeting triggers, neuro-ICU patients were significantly more likely to have withdrawal of life-sustaining treatments (19.4% versus 8.0%, p < 0.001).

Next steps include a qualitative research project to explore palliative care needs in the neuro-ICU from the perspectives of family members and clinicians and identify how best to meet those needs. We have interviewed a family member, a...
physician, and a nurse for 15 neuro-ICU patients to explore their perspectives on palliative care needs. We are currently in the process of analyzing these data.

As we continue our work with severe acute brain injury patients and their families, we are hopeful that findings from these studies will help us develop educational resources and quality improvement tools. Our vision is that all patients admitted to a neuro-ICU with severe acute brain injury will not only receive standardized high-quality evidence-based treatment, but equally standardized high-quality communication, social support, and preference-based treatment.

A Comprehensive Critical Communications Curriculum for Residency Education Using Multimedia Tools—Caroline J. Hurd

Effective and empathic communication is at the heart of providing patient- and family-centered care and is an important core competency for all residents as identified by the Accreditation Council for Graduate Medical Education (ACGME).41 Studies show that when done well, good communication builds trust, engages people in their health care decisions, better aligns treatment plans with goals, and improves patient and family satisfaction.42–45 Medical schools have undergone tremendous reform in the last decade and teach multimodality interactive communication skills earlier in training, however, residency programs have faced significant barriers incorporating this curriculum into day-to-day patient care demands.46 In the Next Accreditation System (NAS), the ACGME emphasizes competency-based outcomes to assess a resident’s developmental progress in performing key Entrustable Professional Activities (EPAs). Critical communication skills such as discussing serious news and conducting a family conference will be important EPAs for many specialties, and residency programs are looking for innovative strategies that can deliver learner-centered material closer to the point of care.6

Our Comprehensive Critical Communications Curriculum will focus on two EPAs; conducting family conferences and discussing serious news. The curriculum is grounded in the successful VitalTalk method using simulated practice but will also integrate innovative multimedia just-in-time learning tools such as a smart phone application and animated “how-to” video.47 Internal medicine and pediatric residents will participate in the curriculum during inpatient rotations so these new skills can be applied immediately in real time. The program contains four elements: self-directed modules about the communication framework, responding to emotion cues and the just-in-time learning tool; small group practice sessions with simulated patients guided by trained faculty facilitators during the first week of their rotation; observed encounters using the just-in-time multimedia tools and a structured observation process; and a procedure tracking system that includes a self-assessment and faculty evaluation for the EPA. The project will be evaluated by the formative and summative outcomes of residents in these two EPAs as well as semistructured qualitative interviews of residents and faculty to understand the acceptability and usability of the curriculum and multimedia tools.

The first year of the project focused on garnering support and enthusiasm from key stakeholders; program directors, faculty, and residents. From the beginning, we worked with program leadership to determine their educational priorities so that we could align and adapt our project to their needs. With their endorsement, we designed the EPAs and a coinciding faculty rubric, and each program has now incorporated these EPAs into their new competency based assessments. Once we had support from program leadership, our focus shifted to our second stakeholder, the faculty. Based on their feedback, we used creative solutions to protect resident learning time, assure patient care coverage, align with faculty interests, and equally distribute teaching commitments. For example, internal medicine interns will attend a half-day workshop on the first day of their ICU rotation, when all senior residents are present for coverage. The workshop will include family conference skills practice but also cover central line simulation and bedside rounds training, which were other curricular priorities for faculty. The workshop will be facilitated by a cohort of critical care faculty champions who are specially trained and who are not on service. Finally, we enlisted residents from our program to beta-test the multimedia tools, help create a choose-your-own-adventure module for responding to emotion cues, and design faculty development workshops. Our curriculum launched in February 2016 with the first cohort unanimously rating the training a 5 of 5 in terms of building new communication skills. In the coming months we plan to track the developmental progress of residents over the course of their rotation and if successful, we hope to expand the curriculum to other residency programs within our health system as a catalyst for institutional cultural transformation in the way we care for patients and families.

Which Palliative Care Quality Measures Improve Patient-Centered Outcomes?—Arif H. Kamal

Palliative care has achieved remarkable growth, with clinical services present in 66% of all hospitals.48 Despite such growth, a standardized clinical approach across the discipline does not yet exist. For example, when a specialty palliative care team is asked to conduct a family meeting and goals of care discussion, is it considered “comprehensive” to perform a symptom assessment prior to the discussion, or “distracting and out of the spirit of the consult request?”

Critical to understanding the preferred approach is an evidence base that links performance of specific care processes (e.g., symptom assessments in all patients, irrespective of the reason for consult) with improvement in outcomes that matter (e.g., quality of life, length of stay). The care processes and associated quality measures with the greatest impact on the experiences of patients and their caregivers can then be prioritized.

Importantly, such prioritization of quality measures does not naturally exist in palliative care. One reason is that the number of published measures is overwhelming. We recently performed a systematic review of published quality measures for palliative care and found 284 quality measures from 11 distinct measure sets.49 This large number parallels the expanding cohort of measures available across all of health care. For example, the Agency for Healthcare Research and Quality (AHRQ)-sponsored National Guidance Clearinghouse alone lists more than 2,700 individual guidelines and associated quality measures.50 The National Quality Forum (NQF) has aggregated these quality measures into portfolios.
showing that 70 distinct portfolios of quality measures reside in their Quality Positioning System.\textsuperscript{51} alone.

Performing research that prioritizes quality measures through their ability to impact outcomes of importance, requires data on quality of care that is both representative of real-life, community-based practice, and which is substantial enough to draw conclusions. We have developed the infrastructure to collect data on quality of care near point-of-care in community-based delivery, called QDACT-PC (Quality Data Collection Tool for Palliative Care).\textsuperscript{52} QDACT-PC is an iPad\textsuperscript{TM}-based data collection system that simultaneously populates a registry of care processes, quality measure adherence, and patient and health system outcomes. Data from QDACT-PC populates a registry on quality in which we can study the link between processes of care and improvement in patient-centered outcomes. After implementing the system within a large-scale quality improvement collaborative, the Global Palliative Care Quality Alliance, we have expanded the program into five sites within the Palliative Care Research Cooperative Group (PCRC), the first multisite clinical research collaboration in palliative care.

We have collected data on quality measure adherence across 5 sites within the PCRC and 13 sites within the GPCQA. Quality measures within the QDACT\textsuperscript{TM} system include those from several nationally recognized sets, including AAHPM’s Measuring What Matters Initiative,\textsuperscript{53} the National Quality Forum endorsed list, and the PEACE measures.\textsuperscript{54} To date, our registry includes data from more than 4,600 patient encounters across more than 2,000 unique palliative care patients. Importantly, the registry includes the patient experiences and health services delivery data across rural, suburban, and urban organizations across many corners of the country. Furthermore, a variety of diseases, conditions, and patient demographics are represented.

We are now in the process of analyzing the data to establish benchmarks and ranges for quality measure adherence, using the data to inform the development of clinical decision support that engages clinicians in the performance improvement process, and then linking quality measure adherence to patient- and health systems-level outcomes. We hope that the findings will inform palliative care leaders about the utility of current quality measures in improving the experience of patients with serious illness, while highlighting gaps in measures that are needed to comprehensively reflect what we believe as a discipline is high quality palliative care. Much work remains to be done, and performing this research in a collaborative, multisite manner makes it such a worthwhile endeavor.

Community-Based Palliative Care Implementation in the San Francisco Department of Public Health—Anne L. Kinderman

Public health systems have historically lagged significantly behind similarly sized not-for-profit health systems in the development of palliative care services. For example, in 2015, only 59\% of public hospitals reported offering palliative care services, compared with 78\% of large not-for-profit hospitals.\textsuperscript{55} For the millions of uninsured and underinsured Americans who rely on public health systems for their care, this creates disparities in access to specialty palliative care services. For example, in San Francisco, residents who depend on the Department of Public Health for health care currently only have access to specialty palliative care services in one acute care hospital and one skilled nursing facility. Because patients receive the majority of their care outside of these settings, this substantially limits their access to palliative care services over the course of their lives.

Reports from public hospital palliative care programs suggest that many care for a large proportion of patients with cancer.\textsuperscript{56–58} Landmark studies demonstrating the benefits of providing early palliative care to patients with cancer suggest that these patients would benefit from community-based palliative care (CBPC) services, and professional organizations such as the American Society of Clinical Oncologists now identify palliative care as an important part of standard cancer care for patients with metastatic cancer or high symptom burden.\textsuperscript{59} Recognizing the potential benefits and current service limitations, we sought to investigate the feasibility and potential impact of offering CBPC to patients with cancer in our public health system.

We performed a retrospective analysis of patients with cancer who received cancer care in our system and who died between 2010 and 2013. Using data from the hospital tumor registry and utilization data from the finance and quality management departments, we examined the care utilization patterns of patients with cancer in the last 6 months of life. We found that of the 403 patients who died in the 3-year period, 76\% were admitted for acute care in the last 6 months of life, and nearly half were admitted in the last month of life. Thirty-three percent (33\%) of patients died in the hospital, and 16\% were admitted to the ICU in the last month of life. These end-of-life hospitalizations were costly (average $25,800), and represent opportunities to improve the quality and efficiency of end-of-life care provided to our patients.

This analysis helped to form the basis of a business plan that projects the fiscal impact of early palliative care services for patients with cancer in our public health system. Based on the experience of community-based palliative care programs serving patients with cancer, which have consistently demonstrated 30\%–70\% reduction in unnecessary health care utilization at end of life,\textsuperscript{60,61} we estimated that a new palliative care team caring for 150 patients with cancer in our system could expect to impact the end-of-life utilization patterns of 50 patients, resulting in 38 avoided admissions, or $980,932, in the first year. Based on this and the compelling evidence of improved quality with early palliative care services, the Department of Public Health committed to providing pilot funding for this new program. The new service will consist of a full-time palliative care specialist nurse practitioner and social worker, and will work collaboratively with hospital administration and oncology to identify patients who would benefit from palliative care, to develop the service model, and to define outcome metrics.

Although there are compelling arguments for providing early palliative care for patients with cancer, there is also evidence that suggests that patients with noncancer diagnoses also benefit from CBPC.\textsuperscript{62} For this reason, the second phase of the project will include a comprehensive palliative care needs assessment across the San Francisco Health Network, focusing on seriously ill patients’ experience, and the challenges that their providers face in meeting their needs. Informed by a growing body of reports describing CBPC models, we will develop a plan to improve care for seriously
ill patients in our system, in the most effective and efficient manner. To date, this project demonstrates that even in safety-net health systems with limited resources and vulnerable patient populations, compelling arguments can be made for expanding palliative care services.

Promoting Palliative Care through Intensive Communication Training for Generalist Clinicians—Elizabeth L. Lindenberger

The demand for palliative care has grown dramatically over the past decade as palliative care consultation has been linked to improved quality of care and lower costs. With this rapid growth comes a major workforce shortage of palliative care physicians, nurses, and professionals of all disciplines, thus posing major barriers to the care of seriously ill patients.

A core service of palliative care consultants is eliciting patients’ preferences and goals of care and aligning treatments with those goals. In most cases, these discussions may be led effectively by providers of any specialty trained in communication, and thus such discussions are considered “primary palliative care.” Skilled communication is a core component of primary palliative care, and yet the majority of physicians and nurses receive no formal training in communication and lack the skills for navigating challenging conversations. The medical literature demonstrates that communication skills can be learned. Geritalk, a communication skills training based on the VitalTalk model, was developed to improve communication skills with seriously ill older patients and their families and has resulted in objective improvement in skill use during family meetings among physician trainees. This Sojourns project aims to promote primary palliative care for generalist providers and nurses, caring for older patients with serious and life-limiting illness, through communication skills training. Clinician groups include: primary attending physicians, i.e., hospitalist and outpatient providers caring for high-risk patients, and palliative care nurses who will serve as communication trainers and liaisons to acute care bedside nurses.

This project aims to promote primary palliative care within one health system through the development of an advanced communication course, Geritalk, adapted for targeted generalist clinicians. As a first step, we conducted a broad communication skills needs assessment of hospitalists at two academic medical centers. We are now pilot testing and evaluating a Geritalk course designed for hospitalists (Hospitaltalk). Similarly, we are adapting the course to meet the needs of primary care providers (physician and nurse practitioner) in an interdisciplinary outpatient primary care clinic developed to care for the medical center’s most chronically and seriously ill patients (PACT). To promote primary palliative care communication skills among nurses, we are implementing a communication course (CommuniCare), designed for palliative care nurses who will then serve as nurse communication champions for general acute care nurses. Last, in order to promote ongoing skills maintenance and improvement, we will develop a longitudinal coaching model for clinician trainees.

Our survey of hospitalists at two academic medical centers revealed multiple self-perceived gaps in communication needs. Only 14% of hospitalists reported feeling “very confident” managing conflict during family meetings, and only 34% of hospitalists reported bringing up information regarding prognosis during conversations with their seriously ill patients. Our pilot Hospitaltalk course demonstrated improved confidence in all domains of communication skills, e.g., giving bad news to family members about a loved ones’ illness and leading family meetings. Similarly, our Geritalk training for 10 outpatient providers (physician and nurse practitioner) demonstrated broad improvement and satisfaction. To improve nursing communication skills, CommuniCare was piloted as two 1-day courses training 14 palliative care nurses and resulted in improved skills confidence. Significant modifications were made between the two courses based on nursing feedback regarding their training needs and learning style preferences. Lessons learned include the importance of interprofessional faculty/staff training for course leadership to meet high demand and unique needs of various clinician groups and the need for innovative models of course scaling and skills maintenance/growth over time, e.g., longitudinal coaching.

Symptom Burden and Palliative Care among Patients with Multimorbidity—Lynn F. Reinke

Research on the provision of palliative care has largely focused on patients with disease specific conditions such as advanced cardiac and pulmonary diseases, AIDS, and cancer. As patients age, they often accumulate diseases that increase their risk of death, however that attribution cannot be made to one condition. Patients with multimorbidity are extremely common, but may not be identified as being at high risk of death. In 2012, the Department of Veterans Affairs (VA) introduced to primary care clinicians a prognostic model called the Care Assessment Needs (CAN) score that was developed and validated using information from the nearly 5 million veterans receiving primary care within VA facilities. The score estimates probability of death or hospital admission within a subsequent 12-month period for every veteran receiving primary care within VA clinics. The goal of the score is to help primary care teams identify patients who may benefit from enhanced care assessment and clinical management. Among 241,917 patients with a CAN score higher than 95% only 0.6% received palliative care services and 0.2% hospice care. This implies that few patients at high risk for a life-threatening event are identified as needing palliative care. The CAN score provides an opportunity to identify patients who are at considerable risk of death or hospital admission in a patient-centered, nondisease specific approach.

Our goal is to assess the symptom burden and quality-of-life among patients with high CAN scores (defined as the top 10% at risk for hospitalization or death) and determine whether patients with high CAN scores receive symptom assessment and delivery of care consistent with palliation of symptoms at the end-of-life. The knowledge generated from this study will inform operational partners how to better appropriate resources to deliver high-quality palliative care and assist policy makers on developing novel ways to identify target populations who may benefit from palliative care services. In addition, there is a growing emphasis with the development of accountable care organizations to use population based approaches to identify patients who may
benefit from additional services, including palliative care, and allocate resources to those individuals.

We conducted cross-sectional telephone surveys and structured interviews to randomly selected patients with a CAN score of 90 or above enrolled in primary care clinics in the VA Health Care System. We recruited 503 patients across 4 geographical regions of the United States from the VA Corporate Data Warehouse. Patients were mailed an information sheet and an opt-out card 30 days prior to a scheduled appointment in the primary care clinic. We telephoned patients 2–5 days after their clinic appointment, reviewed the information sheet, and asked to conduct a telephone interview. If patients agreed to participate, we administered two surveys: The Memorial Symptoms Assessment Scale–Short Form (MSAS-SF) and the SF-12 to assess quality of life. Several structured questions were included about their symptoms, whether their most burdensome symptom was being treated, and their understanding of palliative care services.

Data collection was completed December 31, 2015. Preliminary results support the hypothesis that patients with multimorbidities report multiple symptoms and poor quality of life. Preliminary analysis of the structured survey questions found that 145 (29%) of patients identify pain as the most bothersome symptom and dyspnea (n = 57; 11%) as the second most bothersome symptom. Among 503 patients, only 348 (70%) report their primary care physician is addressing their most bothersome symptom during the recent clinic visit. Patients (n = 330; 66%) report they are receiving some type of treatment for their most bothersome symptom. This finding supports standardization of symptom assessment and management in primary care settings to ensure all patients’ symptoms are addressed and treated.

Only 87 (17%) patients have either heard of or report having some understanding of palliative care. This finding, although not surprising, supports the importance of educating the lay public on the concepts and benefits of “supportive” care. Our end goal is to identify gaps in care and opportunities to improve the delivery of primary palliative care to patients at high risk of 1-year hospitalization or mortality.

Conclusion

The Cambia Health Foundation Sojourns Scholar Leadership Program is a novel initiative to develop and curate the next generation of leaders in the field of palliative care (www.cambiahealthfoundation.org/programs/sojourns). The diverse projects from the inaugural cohort of Scholars reflect the many areas of palliative care program development, education, clinical care, and research that require careful thought and study. Continued development of palliative care leaders will ensure that an adequate and prepared infrastructure is in place to care for all patients with serious illness and their caregivers.

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Author Disclosure Statement

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