Title
Improving the Quality of Palliative Care through National and Regional Collaboration Efforts

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Peer reviewed

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Abstract

Background—The measurement and reporting of the quality of care in the field of palliation has become a required task for many health care leaders and specialists in palliative care. Such efforts are aided when organizations collaborate together to share lessons learned.

Methods—The authors reviewed examples of quality-improvement collaborations in palliative care to understand the similarities, differences, and future directions of quality measurement and improvement strategies in the discipline.

Results—Three examples were identified that showed areas of robust and growing quality-improvement collaboration in the field of palliative care: the Global Palliative Care Quality Alliance, Palliative Care Quality Network, and Project Educate, Nurture, Advise, Before Life Ends. These efforts exemplify how shared-improvement activities can inform improved practice for organizations participating in collaboration.

Conclusions—National and regional collaboratives can be used to enhance the quality of palliative care and are important efforts to standardize and improve the delivery of palliative care for persons with serious illness, along with their friends, family, and caregivers.
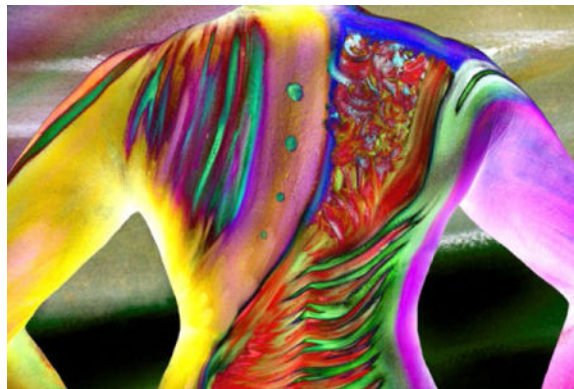
Graphical abstract

Photo courtesy of Lisa Scholder. Road Between Art, $16'' \times 24''$.

Introduction

Over the last few years, use and acceptance of palliative care have been growing for the complex care and needs of patients with cancer and their loved ones.[1] This reflects an increased understanding and acceptance of the care philosophy, the value of interdisciplinary teams that focus on the patient and his or her family as the unit of care, and the understanding that the goals of palliative care align with the priorities of all stakeholders.[2] More patients are receiving palliative care because the scope of practice has expanded from community-based hospices to inpatient hospitals to the offices of primary care physicians, and the number of health care professionals seeking specialized continuing education and support to improve palliative care has increased.[3] In parallel with this clinical growth, collaborations to improve the quality of palliative care are also becoming more common, aiming to share data across sites and settings to translate quality improvement activities across the discipline.[4]

Quality-improvement collaborations aim to clarify how care is delivered and how care might be enhanced through realistic and sustainable interventions. The challenges to such collaborations vary by type and setting of practice, but capturing the diversity of care-

delivery systems is paramount to understanding the variation of palliative care in settings, ranging from community-based organizations to large, academic medical centers. Collaborative initiatives to study the quality of care reflect our increasing reliance on data collection and analysis to understand broader patterns across health care, whether for program development, reimbursement, health services research, or quality assessment. Thus, this article will focus on 3 efforts to improve the quality of the delivery of palliative care at regional and national levels.

Global Palliative Care Quality Alliance

The Global Palliative Care Quality Alliance (GPCQA) is a novel, community/academic quality assessment and improvement collaboration for consultative palliative care that aims to[5]:

- Collect data on the quality of care delivery using a standardized, point-of-care delivery approach

- Facilitate conversations between practices of all sizes and locations regarding challenges and sustainable solutions to improve care

- Use a Institute of Medicine–recommended rapid-learning health care approach to simultaneously inform clinical care, quality measurement, and outcomes research

- Monitor patients along the continuum of care

- Allow for benchmarking and sharing of best practices

The GPCQA originally began in 2007 as the Carolinas Consortium for Palliative Care. Realizing the need to test and adopt this model of quality improvement, its founders set out after initial planning in 2005 to establish an academic/community collaboration between Duke University (Durham, North Carolina) and community partners. The Carolinas Consortium for Palliative Care was originally composed of 5 sites throughout North Carolina: Duke University Medical Center (Durham) and 4 palliative care organizations, namely Four Seasons Compassion for Life (Flat Rock), Forsyth Palliative Care (Winston-Salem), Hospice of Wake and Horizons Palliative Care (Raleigh), and Charlotte Hospice and Palliative Care (Charlotte). Data from patients were collected by health care professionals near the point of care, entered into a local database, and intermittently transmitted to a centralized dataset maintained at Duke University for analysis and quality reporting. The information contributed to a growing data resource, the palliative care database (PCD), which is used for quality assessment and research purposes. From 2008 to 2011, a total of 6,957 unique patient data were collected. Data analyses also supported organizational, quality-improvement objectives and descriptive research about the population served by the Carolinas Consortium for Palliative Care, providing proof of concept that collecting data on quality is feasible in community settings and that these data can inform both clinical practice and institutional priorities in community-based palliative care.[6] However, data collection processes were inefficient and the data collected did not always map to emerging quality measures. Further, a need exists to expand beyond the Carolinas to include partners from across the United States and the world so as to represent greater diversity in practice and

patient needs. A contemporary-based solution was needed that could be electronically implemented in various institutions outside the region.[7]

In 2012, the Quality Data Collection Tool (QDACT) for palliative care was created, leveraging an iterative design in which modular components could be changed as quality measures in palliative care evolved. To develop a quality-assessment tool applicable to everyday practice, 6 steps were involved.

The first step was to review the experiences from participants of the PCD project.[6] This proof-of-concept pilot confirmed that collecting data on quality was feasible in community settings.[5]

The second step was to perform a systematic review of all published quality measures relevant to palliative care, supportive oncology, and end-of-life care to identify measures from which the Consortium could choose to establish priorities for assessment.[8]

The third step was to develop a list of validated tools from a literature review that would inform these quality measures. We aimed to incorporate tools familiar to palliative care providers, when available, like the Palliative Performance Scale. In some instances, the Carolinas Consortium for Palliative Care added metrics and associated data elements based on group consensus.

The fourth step involved developing QDACT, an instrument that demonstrated scalability across expected future changes in the collection and sharing of data relating to palliative care. Electronic health systems and platforms for collecting data evolve and change, so it was important that the tool be generic and operable on different — rather than specific — operating systems, computer hardware, or Internet platforms and be compatible with diverse information technology resources used by palliative care programs nationwide. This process included the development of a data dictionary to support the quality measures.

The fifth step was to test the entire process, from data collection to transmission, storage, analysis, and management; in addition, the process was tested to ensure that it conformed to the highest data security standards for protected health information, including those of the Health Insurance Portability and Accountability Act. This included thorough understanding of the challenges to data security that stem from both hardware and software used at the point of care as well as the potential risks of transmitting data over diverse networks to a shared database.

The sixth step was to expand the project and test its usability on a national scale.

The Carolinas Consortium for Palliative Care was renamed GPCQA in 2014, and it has 14 members who represent community and academic settings and span outpatient and inpatient palliative care programs. Reporting on quality metrics is performed each quarter for all sites, with a feedback loop to improve graphics and visual features. More than 33,000 patient encounters are represented in the database. The quality reporting has been used to support grant funding, to demonstrate the value of palliative care to hospitals and partnering

organizations, to understand the patient population served at each participating institution, and to inform quality-improvement projects.

QDACT displays real-time, immediate feedback via a color-coded alert system while having built-in logic to help inform clinical decisions while health care professionals enter data. For example, a color-coded system reflects whether responses meet an alarm threshold, which is an evidence- or consensus-based parameter (eg, pain score > 4 out of 10). At that point, a screen opens to prompt the user to input what treatments have been offered, if any, and a list of available evidence-based options are displayed. In this example, the alert color (red) will remain present until the pain is brought below the threshold. Other aggregate reports include longitudinal summaries customizable to the health care professional and his or her organization. Members of the GPCQA can request reports that provide both numerical and graphical presentations of descriptive statistics on patient needs, conformance to quality measures, comparative performance between reporting levels, and longitudinal changes. Reports under development include those aligned to national quality measurement initiatives (eg, National Quality Forum, American Academy of Hospice and Palliative Medicine's Measuring What Matters, Physician Quality Reporting Structure), financial projections, and cost-avoidance reports.

This infrastructure has been used to conduct several quality-improvement projects. One project simultaneously measured and assessed adherence to quality measures for timely assessment and management of pain, dyspnea, and constipation. Using reports tailored to the performance of individual health care professionals along with peer-related benchmarks, and then confidentially sharing those reports with those health care professionals, we observed an improvement of the timely management of these 3 important symptoms to levels above 95%. Longitudinal data collection will inform whether these results are long lasting.

Another quality-improvement project involved assessing spirituality and existential distress during the first palliative care visit in all care settings. Using a goal of more than 75% for the completion of the spiritual assessment, the results of the project demonstrated 80% compliance with completing the spirituality question across all of the providers within the GPCQA.

The GPCQA is also looking to expand its membership. Further plans include customized modular build-outs as part of QDACT, expansion of reporting features, integration with electronic health records (EHRs), introduction of a mobile application, and features that enable programs to pull data directly from the software platform. As the landscape of quality measure reporting increases in an era of value-based health care delivery, the GPCQA will look to continuously evolve its efforts to minimize the burden of data collection by health care professionals while maximizing the return on investment to health care professionals through reports, information to support program growth and sustainability, and financial benefits that reward health care professionals for actively promoting a culture of quality assessment and improvement.

Palliative Care Quality Network

The Palliative Care Quality Network (PCQN) is a continuous learning collaborative committed to improving the quality of palliative care services provided to patients and their families. The PCQN was established in 2009 by 20 established palliative care services in California with a shared vision for improving the quality and value of care. The PCQN developed a core dataset that includes care processes (eg, psychosocial assessments) and patient level outcomes (eg, symptom scores) that all members collect on every patient visit. Data are entered into the secure, web-based PCQN database that analyzes data and produces custom reports in real time for individual teams, with comparisons to the entire PCQN. PCQN data allow for coordinated, quality-improvement projects, benchmarking, and the identification of best practices.

The PCQN is composed of 34 palliative care teams from hospitals across the United States and includes community, academic, and public institutions. To date, 19 palliative care teams collect and submit data to the PCQN database and use those data to monitor and improve care. The PCQN database includes more than 13,000 patient encounters.

An important goal of the PCQN is to create and foster a professional community that contributes to the growth and sustainability of palliative care teams and the professional development of the health care professionals that staff them. The PCQN achieves this goal by providing education in clinical care, leadership, team dynamics, and self-care, creating a forum for members to share successful strategies, offering a software program to calculate the financial impact of palliative care at each institution, and establishing a supportive network of like-minded health care professionals.

Guided by the goals of the prospective collection of operational and clinical outcomes data to support real-time patient care and quality improvement, efficiency, and adherence to national guidelines, including the NCP and NQF, the PCQN undertook a modified Delphi process to develop the PCQN core dataset. Overall, the 20 founding palliative care service members collected 96 unique data elements. Through a survey of all members, the PCQN identified 48 "must collect" elements. The PCQN data committee evaluated these elements against published preferred practices to create a 23-item core dataset that includes demographics, processes of care, and patient-level clinical outcomes, including daily symptom scores. The data committee also created a data dictionary to define each data element to ensure consistency across health care professionals and care sites.

A key goal of the PCQN was that the database would include all data that teams needed to collect; no PCQN member would need to maintain a secondary database. To that end, the PCQN adopted optional data elements requested by individual teams for monitoring care at their site. To date, the PCQN has added 22 optional data elements.

The PCQN then developed a secure, web-based database for convenient data entry. PCQN members directly enter data at the point of care into any Internet-connected device or on paper for later data entry. Teams can also collect PCQN data in the EHR, download those data to a spreadsheet file and then upload the file to the PCQN. When data are entered into the PCQN database, they are included in analyses.

The PCQN is collaborating with teams using several EHR platforms to fully integrate the collection of these data. Each member organization owns its data and can download all of the data at any time to a spreadsheet. Data are confidential; only member organizations know which data are theirs.

The PCQN database performs analyses that compare data from the entire network. Members can generate 4 types of summary reports in real time, including reports on demographics, processes of care, disposition and length of stay, and symptoms. Trend reports of data over time and member-comparison reports show the data of the member organization highlighted alongside the unidentified data of the other member organizations. The PCQN is also creating reports that will allow members to compare themselves with others in their health care system. In addition, members can submit information about the structure of their team and characteristics of their institution to compare themselves with similar teams as well as to the entire database.

The PCQN database also produces reports on data completeness and identifies missing data so that members can monitor data-collection efforts. PCQN data align with the Measuring What Matters measures of the American Academy of Hospice and Palliative Medicine/ Hospice and Palliative Nurses Association have been used by members to achieve The Joint Commission advanced certification in palliative care.[9]

The PCQN has developed a financial software program, CaseMaker PCS (San Francisco, California), to calculate the financial outcomes of palliative care at each member institution. CaseMaker PCS combines PCQN data with financial data supplied by member institutions to produce an editable summary of the financial impact of the palliative care team's work. Combined with outcomes data demonstrating quality and comparative data on team composition, the financial analysis information provides palliative care teams information needed to demonstrate value and proof for sustaining and growing their service.

A PCQN quality-improvement collaborative was launched in 2014 with the goals of providing education in quality-improvement methods and using PCQN data to drive coordinated quality-improvement projects. Through quality-improvement workshops at biannual conferences, monthly conference calls, and ongoing mentoring, teams in the collaborative share strategies, challenges, and successes to advance a quality-improvement project. Nine PCQN teams are participating in the first PCQN quality-improvement project, which is focused on improving pain management (a patient-reported outcome).

PCQN data show that, at baseline, 69% (range, 62%–80%) of patients with moderate or severe pain on the day of their initial palliative care assessment had an improvement in their pain by the second palliative care assessment, but only when that assessment occurred within 72 hours of the first. Through the quality-improvement collaborative, participants have identified and tested a number of strategies aimed at improving pain management, including seeing patients with pain early in the day, contacting primary teams and nurses with recommendations or writing new orders immediately after seeing a patient in pain, and conducting follow-up visits in the afternoon to reassess pain and amend recommendations or

orders. Members are monitoring these processes as well as their associated daily pain scores to determine the success of each test of change.

To date, improvements have been difficult to achieve, but the variation in performance is helping to identify additional targets, including the value of addressing anxiety in patients with pain, and the project is ongoing. Members with better outcomes share strategies with others on each monthly conference call, struggling members are provided ideas about how to overcome stumbling blocks, and regular calls motivate all members to keep the project active and advancing.

Satisfaction with the quality-improvement collaborative is high, with 82% of respondents agreeing that their participation motivated their member organization to engage in quality improvement, and 83% indicating that they were interested in continuing their participation in the quality-improvement collaborative.

The PCQN is growing and is inviting additional palliative care teams to join. The more members, the greater the capacity to benchmark with like hospitals to determine with greater precision which structures and processes of care are associated with better outcomes. The PCQN is developing outpatient and home-based palliative care datasets to link with the existing PCQN database, allowing members to monitor and improve care across settings and over time. The PCQN is also working with vendors of EHRs to create systems for quality data collection within the EHR to be submitted to the PCQN database. The PCQN continues to refine its approach to quality improvement and will engage in additional quality-improvement projects involving more teams.

Improving palliative care is a key goal and, thus, a broad dissemination of effective strategies to improve care is a major focus of PCQN going forward. The PCQN is partnering with other organizations and quality initiatives within and outside of palliative care, including the GPCQA, to improve the quality of care across the field, with the mission of transforming health care by defining and promoting quality palliative care.

Project Educate, Nurture, Advise, Before Life Ends

Project Educate, Nurture, Advise, Before Life Ends (ENABLE) is an evidence-based, telehealth, upstream, palliative care model designed to improve care and quality of life for persons with newly diagnosed advanced cancer.[10] First developed in 1999 as a demonstration project through the Robert Wood Johnson Foundation, Project ENABLE has undergone efficacy and effectiveness testing through 2 randomized controlled trials funded by the National Institutes of Health.[10–13] Because of its demonstrated benefits to patient quality of life, symptoms, mood, rates of survival, and to family caregiver depression and burden, Project ENABLE is a scalable model of care.[14–16] The project was developed and tested in primarily rural, community-based cancer practices; however, little guidance exists on how community cancer centers can integrate this model of early concurrent palliative care alongside standard, curative cancer therapies.

In 2013, through a research scholar grant from the American Cancer Society, we embarked on a 4-year dissemination/implementation project using a virtual-learning collaborative approach in 4 racially diverse settings. The project goals were to:

- Assess current palliative care practices and prepare for organizational/health care system change

- Tailor and implement the evidence-based, concurrent, palliative care model of Project ENABLE

- Use the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework to assess outcomes associated with health care institutions, patients and caregivers, and costs before and after implementation of the model

We chose a virtual-learning collaborative approach for 3 reasons because we wanted to increase access to nationwide sites in predominantly rural areas, examine the effectiveness and scalability of this model in racially and ethnically diverse settings, and modify and hone implementation strategies for future dissemination of the program. In addition, we chose RE-AIM because it is a well-tested framework to evaluate the impact of new public health programs.[17]

The first step was to establish working relationships and procedures to launch a virtual collaborative between the School of Nursing at the University of Alabama at Birmingham, which was the coordinating center, and the 4 sites (Gibbs Cancer Center [Spartanburg, South Carolina], Mitchel Cancer Center [Mobile, Alabama], Birmingham Veterans Administration Medical Center [Birmingham], and the Department of Gynecologic Oncology, Wallace Tumor Institute, University of Alabama at Birmingham). Over the last 2 years, the teams at each institution met every 2 weeks as a group with the coordinating center via video conferencing using an online learning platform. During the intervening weeks, the coordinating center team met to trouble-shoot, develop, and refine processes.

Early steps included defining the essential elements of the Project ENABLE model and working with individual sites to tailor the model's elements to specific institutional cultures and resources. Through dialogue and consensus with sites, we also established implementation measures guided by the RE-AIM framework. However, because RE-AIM was not previously used in the setting of palliative care or oncology, time was spent adapting the RE-AIM framework to suit our model and the population of newly diagnosed patients with advanced cancer and their caregivers.

To measure the capacity of organizational characteristics to implement and sustain Project ENABLE, we adapted the General Organizational Index scale.[18] Data collection included a survey to measure the perceptions of oncologists about early and concurrent palliative care, a tool to examine implementation costs, and a battery of patient and caregiver self-report measures similar to those used in our prior randomized controlled trials.[11,12] Mixed methods were used to collect data, including in-person site visit interviews, web-based surveys, and phone interviews.

We have experienced challenges and successes related to the implementation of this model, and we have learned lessons along the way. For example, each site received a small yearly stipend to offset some initial implementation costs (eg, developing materials, fees related to Institutional Review Boards, salary support for conducting the program), but this stipend was not intended to fully support a new program. As such, institutions have had to envision strategies for supporting their programs beyond the grant period.

As a result of changes in institutional leadership, 2 sites were unable to continue and the 2 replacement sites had to quickly acclimate to the model during the planning year. Implementation studies are uncommon to many Institutional Review Boards, so there were many delays prior to acquiring Institutional Review Board approval in the 4 diverse community institutions (including 1 Veterans Administration medical center).[19] One success included 2 functioning programs that introduced potentially sustainable models of early palliative care concurrent with standard cancer treatment, thus increasing access, as was defined in the original project aims. Another success was identifying promising implementation strategies (guided by the RE-AIM framework) for developing new palliative care programs. The important lessons learned, such as institutional barriers and facilitators of implementation, will serve as a foundation for future progress.

Our future goals within the context of this project are to refine all processes and measures to create a toolkit that could be used by other centers wishing to implement an early palliative care model, either in settings with existing palliative care teams without an outpatient or home-/community-based component or within systems without a functional palliative care model. In addition, we will use the current model and methods as pilot data for a larger implementation grant within an established practice network, such as across the US Veterans Administration health care systems, the Deep South Network for Cancer Control, or a research network such as the Palliative Care Research Cooperative Group.

Discussion

Quality-improvement initiatives reflect the natural evolution of the evidence base in palliative care. Use of palliative care has grown in the last decade, with its roots beginning in the hospice movement in the late 1970s. A defined subspecialty field, with an evidence base for practice that improves daily palliative care, should use implementation and dissemination approaches that routinely include elements of quality measurement (often with validated measurement tools). Federated database systems facilitate the simultaneous examination of both quality and research questions. Administrators, health care professionals, and researchers are beginning to recognize that robust data analytics are crucial for improving patient- and family-centered advanced illness care.

The 3 quality-improvement and dissemination efforts reviewed in this article all use a conceptual model of quality improvement in palliative care to guide their approach, highlighting the importance of collecting uniform data. For example, all 3 efforts require participants to use a federated set of primary data elements defined by a common database dictionary as part of the validated collection metrics. Given the variety of practice settings, clinician types, and stages of disease process represented, this allows for uniformity and

interoperability that ensures that data can be aggregated, compared, and analyzed in the future to better characterize palliative care.

One significant, ongoing challenge for new and existing quality-improvement initiatives is how to make the effort as invisible and integrated as possible amid the fabric of usual clinical operations. As the GPCQA has found, the dual-entry of data elements — once into the EHR for clinical purposes, and once into a registry for aggregation and reporting — is a significant barrier to health care professional buy-in and effectiveness. The seamless integration of validated, quality metric data collection into EHRs is ideal but has major cost and time implications. However, overcoming these barriers is crucial to allow for increasingly robust reporting of data, which can then be used to aid palliative care program development, sustainability, and growth.

Future Directions

Quality-improvement collaborations are expected to continue to grow in the field of palliative care. For established efforts such as the 3 described in this article, this growth will manifest as a focus on how to sustain the initiative in terms of mutually beneficial outcomes, continued innovation, and financial viability. In turn, sustainability will allow for additional innovation, such as developing quality-improvement initiatives focused on patient-reported outcomes and caregiver outcomes. Programs may join forces and align with other initiatives to allow for larger learning networks and more robust data. By contrast, small, issue-specific collaborations may develop where practices are less unified, such as when palliative care is incorporated into alternative payment model structures (eg, medical homes, accountable care organizations). Similarly, local efforts may develop among health care professionals in a single region so that a single patient's trajectory can be tracked — and quality of palliative care improved — across multiple care transitions and health care systems. As the push for meaningful use and interoperability of electronic health records continues, uniform and secure data collection and sharing (per the requirements of the Health Insurance Portability and Accountability Act) should continue to improve.

Conclusions

Health care leaders and those specializing in palliative care are faced with the challenge of providing consistent, high-quality care that meets the needs of patients and their family, friends, and caregivers. This challenge can be aided by belonging to a community of like-minded leaders focused on cooperative efforts to define, measure, and improve the quality of palliative care delivery. Clinical palliative care is a collaborative effort, so alliances and networks of engaged health care leaders and physicians are needed to prioritize the care processes that consistently improve the experiences of patients with serious illnesses.

Acknowledgments

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