QDACT

A web-based tool shines a light on quality palliative care

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A disconnect exists between measuring the quality of health-care and the subsequent evidence-based improvements needed to treat patients with serious cancer and their caregivers.[1] Though this disparity persists, methods are evolving to measure quality of healthcare, reflecting an increased focus on aligning current practices with accepted best standards of care, and identifying where opportunities for improvement exist. Duke University Medical Center and Four Seasons Compassion for Life have partnered with the Global Palliative Care Quality Alliance to institute an ambitious plan to standardize quality measurement, promote comparison of data on quality, and share best practices across academic and community palliative care organizations. This approach will position the growing and maturing field of palliative care to meet the increasing demands for high-quality care set forth by healthcare reform. This article describes our underlying approach of rapid learning quality improvement (RLQI), the development of our partnerships, and our novel electronic tool to capture data on quality.

RLQI: Improving Care through Data

A major gap in healthcare persists between identified areas for quality improvement (QI), innovations to address these areas, and then processes to implement these discoveries in everyday care. Historically, QI initiatives have relied heavily on antiquated processes that suffer from two key limitations. First, traditional QI approaches address one measure of change and subsequent, downstream changes in only one outcome. For example, conventional methods do not easily perform simultaneous assessments of several, rapidly implemented changes and longitudinal changes in several related clinical, administrative, and financial outcomes. Second, data collection for information on quality usually relies on either paper-based methods or manual abstractions of retrospective clinical data. This approach is quite cumbersome. Further, real-time analysis is virtually impossible. Together, these limitations reinforce current QI methods within a rigid, retrospective construct that does not have the flexibility needed to dynamically improve the care of patients.

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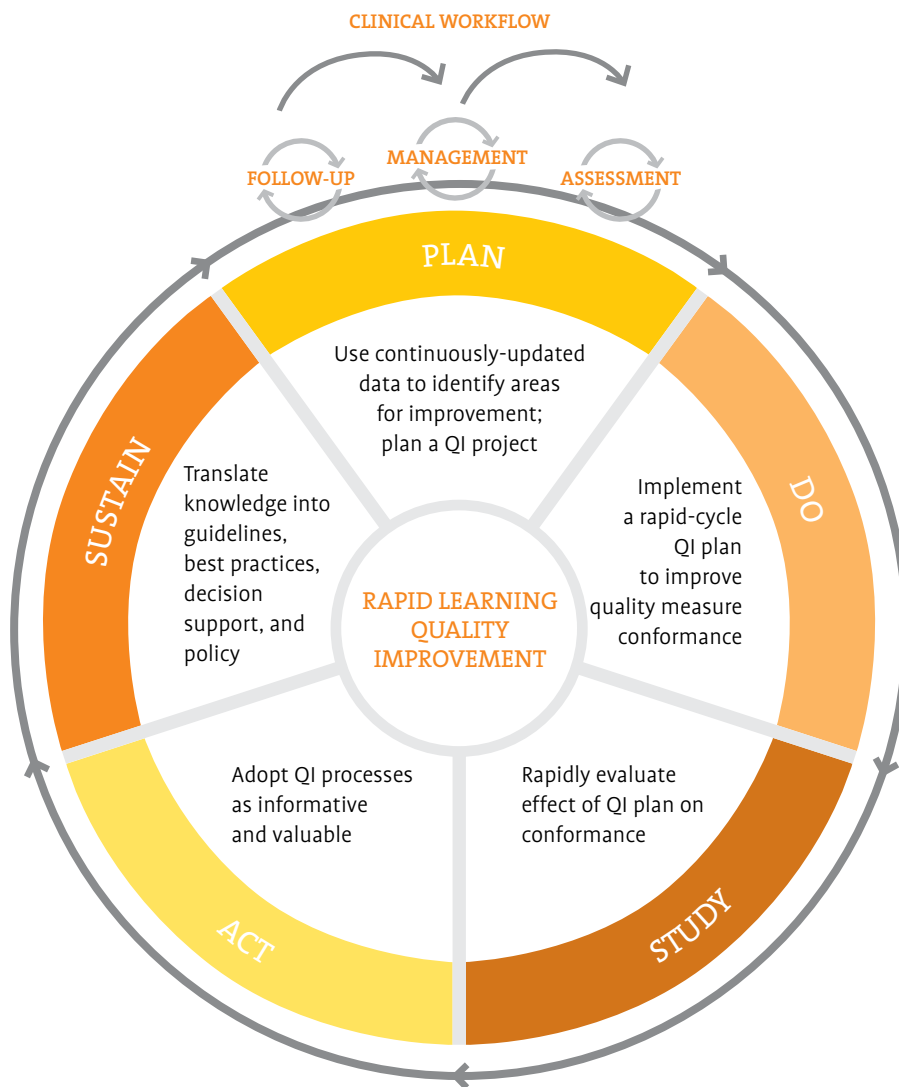
RLQI leverages the core concepts of quality improvement by integrating the Institute of Medicine's (IOM) vision and principles for a rapid learning healthcare system to drive quality improvement (see Figure 1, page 24). This approach requires the principles of:
- Rapid collection, summation, and analysis of data
- Rapid integration of new knowledge back into clinical delivery
- Continuous learning from everyday clinical care delivery.

Just as Rapid Learning Health Systems as proposed by the IOM revolutionized thinking about how new research knowledge is developed, RLQI empowers palliative care organizations to use data on quality to advance how clinical care is delivered. By

Essentially, RLQI allows a clinician to determine and then implement positive processes of healthcare delivery much more quickly than standard QI or research-based methods.

Figure 1. Rapid Learning Quality Improvement Clinical Workflow

CLINICAL WORKFLOW

FOLLOW-UP   MANAGEMENT   ASSESSMENT

PLAN
Use continuously-updated data to identify areas for improvement; plan a QI project

DO
Implement a rapid-cycle QI plan to improve quality measure conformance

SUSTAIN
Translate knowledge into guidelines, best practices, decision support, and policy

RAPID LEARNING QUALITY IMPROVEMENT

STUDY
Rapidly evaluate effect of QI plan on conformance

ACT
Adopt QI processes as informative and valuable

Table 1. Quality Measures Informed by QDACT

QUALITY DOMAIN	PERCENT OF ALL PATIENT-REPORTED QUALITY MEASURES INFORMED BY QDACT	QUALITY MEASURES EXCLUDED FROM QDACT
Structure and processes of care	13/14 = 93%	Structural measures involving team structure and competencies
Physical aspects of care	69/85 = 81%	Measures specific to chemotherapy or radiation treatments in cancer patients, those specific to diarrhea and skin rash, workup for anemia, and invasive interventions for pleural effusion, causes, and treatment of delirium
Psychiatric and psychological aspects of care	12/13 = 92%	Caregiver grief, bereavement, and satisfaction with care
Spiritual and existential aspects of care	2/4 = 50%	Caregiver satisfaction, value of life
Social aspects of care	1/3 = 33%	Family structure, caregiver preference, caregiver satisfaction with patient life stance
Cultural aspects of care	1/1 = 100%	Most not measured by patient response
Care of the imminently dying	1/1 = 100%	Most that involve information sharing with family
Ethical and legal aspects of care	26/31 = 84%	Patient preferences for location of care; informed decision making regarding chemotherapy
All domains and measures	125/152 = 82%	

combining these three benefits of RLQI, clinicians can make actionable decisions that rapidly impact a patient's overall well-being with greater certainty, while determining the effects of a single clinical instrument (such as the web-based assessment tool discussed later in this article) on multiple clinical outcomes.[2] Essentially, RLQI allows a clinician to determine and then implement positive processes of healthcare delivery much more quickly than standard QI or research-based methods. The end result: patients receive the best care possible, as quickly as possible.

Developing a Regional Consortium on Quality in Palliative Care

Recognizing the need to test and adopt this new model of quality improvement, the Carolinas Palliative Care Consortium ("Carolinas Consortium") was created in 2007. This academic and community collaboration was comprised of five sites throughout the state:
1. Duke University Medical Center, Durham, N.C.
2. Four Seasons Compassion for Life, Flat Rock, N.C.
3. Forsyth Palliative Care, Winston-Salem, N.C.
4. Hospice of Wake, Raleigh, N.C.
5. Horizons Palliative Care, Raleigh, N.C.

Each of these locations collected patient-level data on paper, entered this information into a local database, and intermittently transmitted the data to a centralized dataset maintained at Duke for analysis and quality reporting. The information contributed to a growing data resource, which the Consortium called the Palliative Care Database. From June 2008 through October 2011, data from a total of 6,957 unique patients were collected. The Palliative Care Database provided 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.[3] Data collection processes, however, were inefficient and the data collected did not always map to emerging quality measures. The Carolinas Consortium recognized that a web-based solution that would align with expectations for quality monitoring in palliative care was needed.[4]

A Web-Based Solution

In developing a quality assessment tool that would be applicable to everyday practice, the Consortium followed six steps. These steps were accomplished over the course of a year through biweekly telephone conferences and three in-person meetings between the members of the Carolinas Consortium. These members included community palliative care providers and an interdisciplinary team of clinicians, researchers, graphic designers, software programmers, database analysts, and information security experts 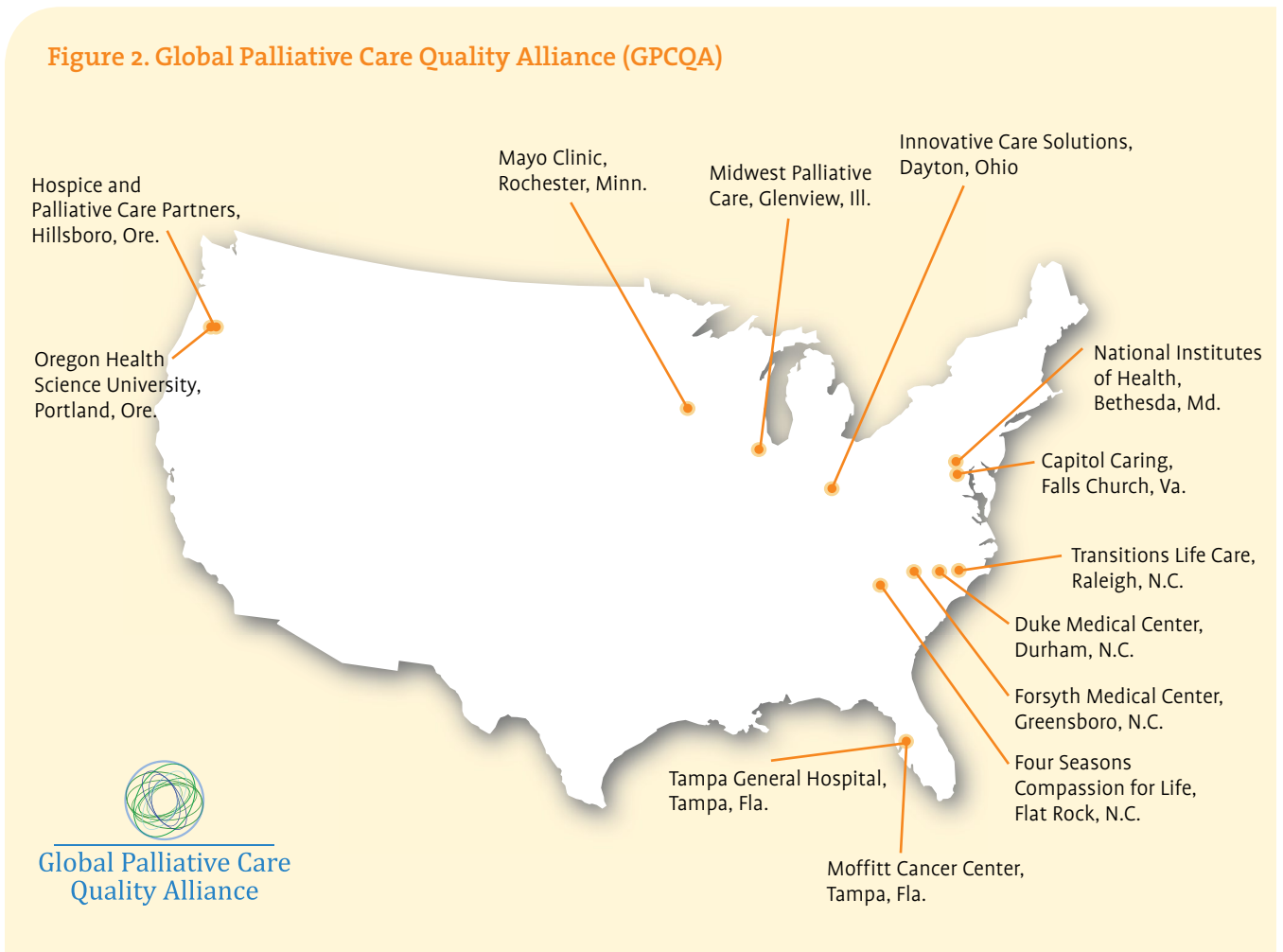to ensure the new system met the rigorous demands of all stakeholders. The development process included conducting a needs assessment of clinicians to ensure that sustainability and validity of data collection practices demonstrate value for the time clinicians spend collecting the data.

Step 1. The Carolinas Consortium reviewed the Palliative Care Database project and then surveyed participating clinicians to identify the strengths and weaknesses of the database and to seek suggestions for improvement. Additionally, during a two-day retreat, the Carolinas Consortium facilitated an in-person group discussion with clinicians and administrative stakeholders from

Table 2. Domains and Components of QDACT

QDACT CLINICAL DOMAIN	QUALITY DOMAIN	NUMBER OF ITEMS	QUESTION SOURCES
Demographics	Cultural aspects of care, structure, and processes of care	20	Consortium-developed, Palliative Care Research Cooperative (http://palliativecareresearch.org); National Cancer Institute Bioinformatics Grid and Cancer Data Standards Registry and Repository (http://cbiit.nci.nih.gov/ncip); Australian Palliative Care Outcomes Collaborative (http://ahsri.uow.edu.au/pcoc/index.html)
Symptom assessment and management	Physical aspects of care; structure and processes of care	50	Edmonton Symptom Assessment Scale (ESAS); Memorial Symptom Assessment Scale (MSAS); two-question depression assessment, Consortium-developed
Advance care planning	Ethical and legal aspects of care	3	Consortium-developed
Psychosocial	Psychiatric and psychological aspects of care; social aspects of care	4	Consortium-developed; The Spitzer QOL Uniscale; the Perceived Family Burden Scale (PFBS); Linear Analog Scales of Assessment (LASA)
Independence & function	Consortium-developed	2	AKPS (Australia-modified Karnofsky Performance Scale); PPS (Palliative Performance Scale)
Spirituality	Spiritual and existential aspects of care	3	Consortium-developed; LASA; Johnson et al. "Are you at peace?" question
Prognosis	Consortium-developed	2	Consortium-developed
Transitions and discharge	Consortium-developed	7	Consortium-developed
Physician Quality Reporting System (PQRS)	None	4	Centers for Medicare & Medicaid Services (CMS) PQRS 2011 Measures

Figure 2. Global Palliative Care Quality Alliance (GPCQA)

Hospice and Palliative Care Partners, Hillsboro, Ore.

Oregon Health Science University, Portland, Ore.

Mayo Clinic, Rochester, Minn.

Midwest Palliative Care, Glenview, Ill.

Innovative Care Solutions, Dayton, Ohio

National Institutes of Health, Bethesda, Md.

Capitol Caring, Falls Church, Va.

Transitions Life Care, Raleigh, N.C.

Duke Medical Center, Durham, N.C.

Forsyth Medical Center, Greensboro, N.C.

Four Seasons Compassion for Life, Flat Rock, N.C.

Tampa General Hospital, Tampa, Fla.

Moffitt Cancer Center, Tampa, Fla.

Global Palliative Care Quality Alliance

each of the five sites to critically inventory lessons learned from the Palliative Care Database and to design and conceptualize improvements to the evolving quality tool.

Step 2. Next, the Carolinas Consortium performed 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.[5] Part of this process was to ensure that data collected would accurately and completely inform the scope of published quality measures found. Further, we needed to confirm that data on quality conformance would truly reflect the definitions, numerators, and denominators as meticulously outlined by the developers in the definitions of the quality metrics. These definitions include aspects of patient populations, timing, and

settings for these measures (see Table 1, page 25).

Step 3. The Carolinas Consortium then developed a list of validated tools from a literature review that would inform these quality measures. When available, the Consortium tried to incorporate tools familiar to palliative care providers. In some instances, the Consortium added metrics and associated data elements based on group consensus. These metrics and data were necessary to ensure that applicability and familiarity of the instrument would extend to palliative care programs outside of the Carolinas Consortium (see Table 2, page 26).

Step 4. The Consortium wanted to ensure that the new system would be interoperable with other large databases to ensure future data comparisons and collaboration. We identified other applicable national and international databases and registries that would

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serve as references and completed the critical crosswalks to standardize definitions and terms. This step is a requirement of a sustainable and broadly applicable rapid learning healthcare system based on patient-reported outcomes.

Step 5. Next, the Consortium began to develop a new instrument that demonstrated scalability across expected future changes in the collection and sharing of palliative care data. Understanding how electronic health record (EHR) systems and platforms for collecting data evolve and change, it was important that we avoid making a new instrument that was operable only on specific operating systems, hardware, or Internet platforms, and instead would be compatible with the diverse IT resources used by palliative care programs nationwide.

Step 6. The Consortium's last task was to test the entire process—from data collection through transmission, storage, analysis, and management—while conforming to the highest data security standards for protected health information. This includes a thorough understanding of the threats to data security that stem from both hardware and software used at point-of-care, as well as the potential risks of transmitting data over diverse networks to a shared database.

The end result of all this work: the Quality Data Collection Tool (QDACT), a web-based, provider-entered, point-of-care quality assessment and reporting tool for palliative care. QDACT was a platform-agnostic, scalable, and open-sourced solution designed for data collection during clinical encounters. The Carolinas Consortium tested the tool from August 2010 through August 2011.

Data security and storage for undertakings like QDACT are a fundamental concern. After conforming to Health Insurance Portability and Accountability Act (HIPAA) and Duke University standards for data protection, the Consortium hired an external security-consulting firm to conduct a threats analysis to test for weaknesses of the data transmission process and the security of the QDACT database. Based on feedback from this analysis, appropriate revisions were made to ensure the utmost protection of each patient's protected health information. Further, the Consortium developed a central database, with corresponding business associate agreements between organizations, which outlined standards for data handling, use, and reporting.

Finally, the Consortium developed a structure for real-time, quarterly, and ad-hoc graphics-based feedback and reporting. The real-time component displays immediate feedback on unmet

needs while providers enter data. For example, a color-code system reflects whether responses meet an "alarm threshold," which is an evidence- or consensus-based parameter (e.g., pain score greater than 7 out of 10). Once the threshold is reached, the clinician is alerted during the current visit and at subsequent visits. Other aggregate reports include longitudinal summaries that can be customized to the provider and the organization. Further, Consortium members requested that reports provide both numerical and graphical presentations of descriptive statistics on patient needs, conformance to quality measures, comparative performance between reporting levels, and longitudinal changes.

The Global Palliative Care Quality Alliance

QDACT's successful implementation into multiple clinical settings throughout North Carolina prompted the Carolinas Consortium leadership to expand QDACT's reach beyond the state (and Consortium) to a national stage. Subsequently, the Consortium has grown into the Global Palliative Care Quality Alliance (GPCQA), which is an expanding multi-institutional collaboration for quality assessment and improvement in specialty palliative care. To date, GPCQA is comprised of 11 academic and community organizations (see Figure 2, page 27). A continually expanding entity, GPCQA is the first palliative care collaboration to perform a nationwide uniform, rapid-learning quality improvement project. Currently, GPCQA is conducting its initial nationally implemented RLQI project to test the impact of a spirituality assessment on patient outcomes.

Last Words

The evaluation and reporting of healthcare data on quality is evolving quickly. Annual changes proposed by payers, regulators, accreditors, and membership organizations require clinicians and researchers to be creative and innovative about how assessing high-quality care can become a routine task. The days of manual chart abstractions and other resource-intensive methods to demonstrate and verify the delivery of quality care are, hopefully, moving behind us because of new approaches that are technology-enhanced and data-empowered. Armed with rapid learning methods and a continuous shift in culture towards regular and rapid quality improvement, collaborations between clinicians and patients are being built, with community and academic centers answering the call to not only do better (walk the walk), but to prove we are doing better (talk the talk). We are fortunate at Duke University and Four Seasons, along with our partners, to be on that journey towards universal high-quality palliative care. ◨

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