Development of a Health Information Technology–Based Data System in Community-Based Hospice and Palliative Care

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Background: Few hospice and palliative care organizations use health information technology (HIT) for data collection and management; the feasibility and utility of a HIT-based approach in this multi-faceted, interdisciplinary context is unclear.

Purpose: To develop a HIT-based data infrastructure that serves multiple hospice and palliative care sites, meeting clinical and administrative needs with data, technical, and analytic support.

Methods: Through a multi-site academic/community partnership, a data infrastructure was collaboratively developed, pilot-tested at a community-based site, refined, and demonstrated for data collection and preliminary analysis. Additional sites, which participated in system development, became prepared to contribute data to the growing aggregate database.

Results: Electronic data collection proved feasible in community-based hospice and palliative care. The project highlighted "success factors" for implementing HIT in this field: engagement of site-based project "champions" to promote the system from within; involvement of stakeholders at all levels of the organization, to promote culture change and buy-in; attention to local needs (e.g., data for quality reporting) and requirements (e.g., affordable cost, efficiency); consideration of practical factors (e.g., potential to interfere with clinical flow); provision of adequate software, technical, analytic, and statistical support; availability of flexible HIT options (e.g., different data-collection platforms); and adoption of a consortium approach in which sites can support one another, learn from each others' experiences, pool data, and benefit from economies of scale.

Conclusions: In hospice and palliative care, HIT-based data collection/management has potential to generate better understanding of populations and outcomes, support quality assessment/quality improvement, and prepare sites to participate in research.
(Am J Prev Med 2011;40(5S2):S217–S224) © 2011 American Journal of Preventive Medicine

Background

Health information technology offers various electronic means of collecting, managing, and storing data. By removing many location-specific requirements, the use of HIT for tasks such as data collection allows these functions to be performed in diverse healthcare settings ranging from the clinic and hospital to community-based organization and home.

The potential benefits of HIT cannot be realized without the development of user-centered HIT systems that feature clinically valuable, intuitive, empowering tools, and that produce reliable, secure, interoperable data.[1,2] Here "users" are all those who may interact with the system, whether through provision of data (e.g., patients); data collection (e.g., clinical staff or researchers); clinical use (e.g., doctors, nurses); or analysis for other purposes (e.g., administrators). To exert maximal impact on healthcare quality and outcomes, user-centered information technology (IT) systems must span the continuum of care, from wellness and preventative care to diagnosis and treatment, through survivorship, chronic illness, and end-of-life care.

Palliative care is commonly defined as health care for individuals with advanced life-limiting illness. Focused

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Figure 1. Model of palliative care integrated into the continuum of care

on improving function and quality of life regardless of the remaining duration of life, it can be provided in conjunction with curative care or as the sole focus of care (Figure 1). Attention to human-factor aspects of the HIT system may be especially critical in palliative care because of its inherently multi-faceted nature (encompassing symptom-focused, psychosocial, caregiver, and spiritual care), frequent provision in the home and community, and dependence on multidisciplinary teams. Just as HIT systems are being developed to support various primary and subspecialty areas of health care, it is also critical to develop discipline-specific HIT systems for palliative care.

Several distinguishing features of palliative care are relevant when considering HIT-enabled data collection. First, palliative care is provided in diverse settings ranging from inpatient consultative services and dedicated hospital units to outpatient programs, community-based institutions, and homes. Continuity is often lacking as patients transition across settings. According to the Center to Advance Palliative Care, in 2008 there were 1486 hospital-based palliative care programs; of U.S. hospitals with at least 50 beds, 59% had palliative care programs.[3]

Utilization of hospice services has been steadily increasing; according to the National Hospice and Palliative Care Organization, an estimated 5000 hospices served 41.6% of all deaths in the U.S. in 2009.[4]

Second, palliative care typically involves a multidisciplinary set of skills; it is provided by care teams comprised of several specialists including physicians, nurses, social workers, psychologists, and chaplains (Figure 2). Third, palliative care has emphasized data collection and data quality less than have other medical specializations typically providing care in the hospital or clinic setting. And fourth, the data to be collected focus on quality of life, symptom control, functionality, psychological and interpersonal concerns, and end-of-life planning—elements that are not well codified.

Historically, hospice and palliative care programs have not been oriented toward research, have not quantified and benchmarked their services, and have not invested heavily in infrastructure for data management. Focused on provision of service in the community, they have had little interaction with traditional quality and research activities; this gap reduces the chance that high-quality data are routinely used to inform best practice.[5] For those institutions which may wish to participate in research, lack of funding and budgetary constraints can prevent acquisition of data-management and HIT infrastructure. Nonetheless, outpatient hospice data have demonstrated improved outcomes when data-driven quality-improvement programs are implemented.[6]

Challenges or barriers to implementing HIT in palliative care, particularly in community-based sites, abound. Fragmentation of the healthcare system creates problems related to loss to follow up, data heterogeneity, and non-standardized procedures. Many provider organizations are small; although they are clinically proficient, they lack financial and technical resources. Standardized research

Figure 2. Interdisciplinary team model of palliative care

methodologies which might support and utilize HIT are virtually non-existent in palliative care. HIT infrastructure, including electronic data-collection and data-management processes, has thus yet to be instituted in most palliative care organizations. Use of HIT for palliative care is primarily concentrated in the inpatient setting, where clinicians and researchers can draw on institutional resources, experience, support, and precedent.[7] This paper describes an academic/community partnership process for developing an HIT-based data infrastructure intended to support quality initiatives and ultimately research across multiple hospice and palliative care sites.

Methods

To begin developing a regional HIT infrastructure in palliative care, an academic medical center with a focus on palliative care in oncology (Duke University Medical Center, Durham NC [Duke]) and a community-based hospice and palliative care organization with a research department (Four Seasons, Flat Rock NC) formed an academic/community partnership. Subsequent partners included a second academic site (University of North Carolina at Chapel Hill, Chapel Hill NC [UNC]) and three community sites in Charlotte, Winston-Salem, and Raleigh NC; this partnership is the "Carolinas Consortium."

The purpose of the "Palliative Care Database" project is to create a HIT-enabled regional data infrastructure that: (1) allows longitudinal tracking of outcomes, as well as analyses of patient characteristics, by site, subpopulation of interest, and in aggregate; (2) supports quality assessment, benchmarking, and monitoring; (3) can meet the needs of diverse hospice and palliative care organizations; (4) helps organizations respond to reporting requirements; and (5) assists policymakers with workforce planning. The project builds on previous efforts at Duke to implement and demonstrate an electronic data-collection infrastructure in outpatient academic oncology,[8–10] and leverages experience in developing a national palliative care quality monitoring program in Australia.[11]

Project implementation comprised two phases (Year 1, Year 2; Table 1). Year 1 activities focused on development of a comprehensive data-collection and warehousing system that uses the site's choice of HIT platform for data collection. Key tasks were to: define data elements, develop a data dictionary, program data elements, integrate the data-collection software with the site's existing data-management software, create a data-collection form, practice point-of-care data collection, establish secure channels for data transfer from the site's server to the Duke server, and perform data-management programming.

Principal activities planned for Year 2 were to: obtain commitment from three additional sites (beyond the initial community-based site and academic site) to join the project and contribute data to the database; continue to develop the system with participation of and input from the new sites; conduct an onsite training seminar at Four Seasons; provide ongoing mentoring to the new sites; develop a file transfer protocol; develop a model for collaboration and data governance (to guide data-sharing across sites); and develop quality initiatives based on evaluation of aggregate data.

**Table 1.** Palliative Care Database activities in the first 2 years

	Months		
	Phase 1		Phase 2
Palliative Care Database timeline	0–6	7–12	13–24
System development and implementation	X	X	X
Stakeholder meetings	X	—	—
Database development, including definition of data elements	X	—	—
Software development (e.g., file transfer protocol)	X	—	—
Consortium bi-weekly teleconferences	X	X	X
Pilot testing of system at Four Seasons	—	X	—
Test of tablet computers and electronic pens	—	X	—
Data collection on 250 patients	—	X	—
Preliminary analyses	—	—	X
Full-scale implementation	—	—	X
Ongoing data collection at Four Seasons	—	—	X
Preparation of new sites for data collection	—	—	X
Planning for data governance and stewardship	—	—	X
Development of quality initiatives	—	—	X

Results

Four Seasons served as the pilot site for Year 1 implementation, although stakeholder meetings included personnel from Duke, Four Seasons, UNC, and local hospice and palliative care organizations. These meetings focused on the database development approach, selection of data elements, and site needs.

Stakeholders agreed on a modular approach that begins with a core set of data elements and allows flexibility to customize data collection by adding site-specific data elements. Data items were intentionally selected to be meaningful across the continuum of hospice and palliative care (i.e., bridging various inpatient and outpatient settings). Data elements were harmonized with those used at UNC, to establish data interoperability for future research.

Once data elements were defined, a data dictionary was developed and corresponding data-collection forms were created and field-tested. A relational database was selected because its architecture served clinicians' needs,
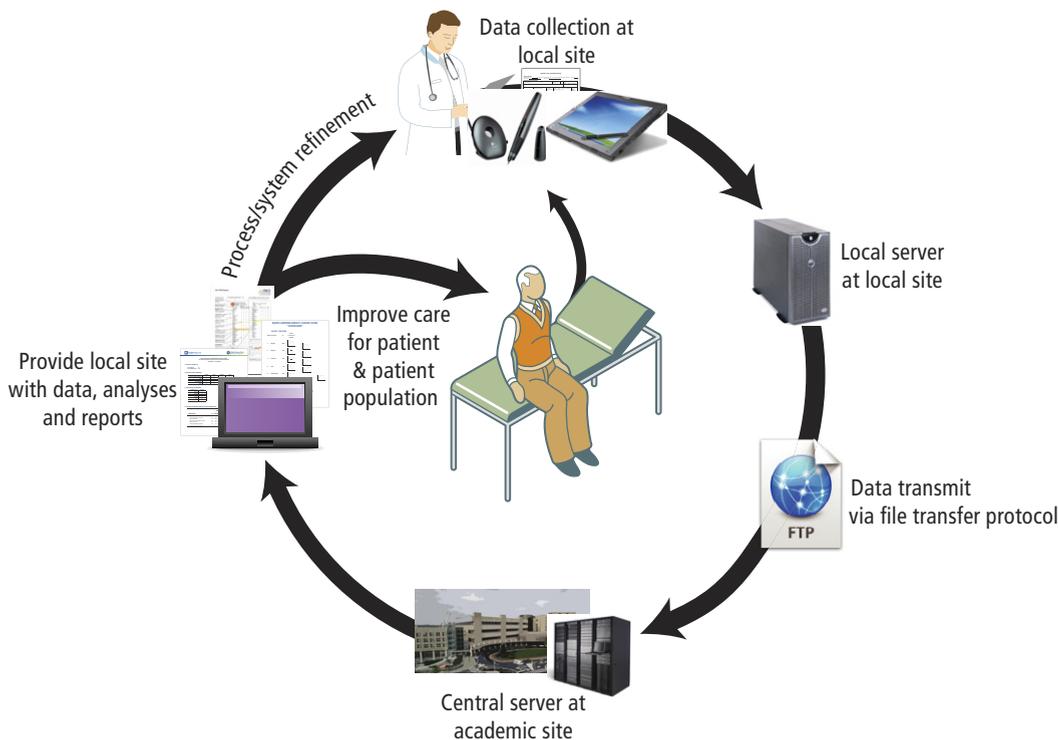
Figure 3. Data flow in the Palliative Care Database Project

met security requirements, and accepted data through a variety of HIT platforms as well as paper-based data collection. The database was initially programmed in Microsoft Access 2003 for pilot-testing, and subsequently transferred to Microsoft SQL Server 2005. Software, data-transfer protocols, and data-control procedures were developed to ensure data security. Data travel from the community site to the academic site for analysis and reporting; iterative feedback informs system refinement and directs analytic inquiries (Figure 3). A project wiki provides participating sites with access to materials (e.g., data dictionary, manual for data collection in palliative care) and facilitates communication.

Initial plans called for deployment of tablet personal computers as the HIT data-collection platform. Piloting of this approach at Four Seasons showed this technology to be infeasible in the mountainous terrain of western North Carolina; loss of signal was a repeated problem. The tablet computer's per unit cost was also a concern, one that might exclude many small-sized organizations from joining the Consortium. Electronic pens were next piloted, and proved to be a more satisfactory option. Mid-level or physician providers used both electronic pens and paper case report forms to complete the data-collection form. Paper-based data collection required subsequent manual data entry into the computer database, to populate the electronic form; electronic pens

eliminate this step by, when docked, automatically downloading data into the form.

In Year 1, Four Seasons collected data on 250 new patients in three hospitals, over 35 nursing homes and assisted living facilities, and the home setting; these patients represented approximately half of the total new-patient population referred to the service during this time period. At the time of this research, nine mid-level providers (five physician assistants, four nurse practitioners) and three physicians were involved in data collection. Average daily census of the palliative care program was 600 patients; the typical patient had a life-limiting illness with a less than 3-year prognosis. Four Seasons uses Suncoast Solutions to assist with administrative data, but will migrate to a true electronic health record, Cerner, in 2011. Preliminary analyses were performed on the 250 Year-1 patients to test the quality and utility of these data.

During Year 2, three additional sites began contributing data to the Palliative Care Database. Representatives from these sites had participated in system development (Year 1) via bi-weekly teleconferences, attended an onsite training seminar at Four Seasons, and received ongoing mentoring. A file transfer protocol was developed for use at these sites. A model for collaboration and data governance, to guide data-sharing across sites, was initiated and is currently under development. In the second year, data were collected on over 1500 new patients, and fur-

ther analyses using these data were performed. Preliminary analyses, which presented data from one site and encompassed 2572 visits from 970 new patients, have been published; these analyses characterize the population, symptom profiles, and change in symptoms after intervention.[10]

Consortium discussions identified quality reporting as a key concern of participating organizations. Members agreed that the data collected should lead to meaningful insights for the hospice and palliative care program, and support clinical quality and performance improvement. To start, nationally defined quality metrics for palliative care were mapped to the database, and reports were generated using these metrics. These metrics were too superficial to provide the depth of insight needed to examine and improve care at Four Seasons. New reports, updated monthly or as needed, were developed to focus on questions generated by the site. For example, the palliative care population was first profiled by major disease category (e.g. cancer, heart failure); symptoms were then profiled by disease category over time and were explored by patient demographics, quality of life, and performance status. An example finding was that African-American patients were twice as likely as Caucasians to report bothersome constipation; this led to the development of revised constipation assessment/management procedures at Four Seasons.

The impact of this change is being monitored. The database was also used to examine, in preliminary fashion, other outcomes such as advance care planning, psychological distress, and caregiver status. In recognition that the Center for Medicare and Medicaid Services (CMS) Physician Quality and Reporting Initiative (PQRI) offers increased CMS payments to providers who report on PQRI metrics, the database was updated to accommodate PQRI measures.

Discussion

While HIT might facilitate improvement in data-management processes, data quality, and research capacity of hospice and palliative care organizations, characteristics of provider organizations create unique challenges to HIT implementation. This ongoing project demonstrates that HIT can be successfully integrated into the clinical flow of community-based hospice and palliative care, and can yield information valuable for clinical and administrative purposes. It also highlights certain factors that demand attention in order to ensure the feasibility and utility of such a system in a complex, multidisciplinary setting. These "lessons learned" may help guide other organizations and consortia as they proceed to incorporate HIT for data-collection and data-management purposes.

"Human factors" proved critical in implementing a HIT-based data-collection system in a community-based hospice and palliative care organization. From the outset, the project engaged "tech savvy" individuals at the pilot site (Four Seasons), soliciting their input into system design and involving them as mentors to new users. Support of these site-based champions was garnered by showing them, in practical ways, how the new system would improve care for their patients. Without local champions, it is likely that staff would have complained about the effort entailed, that staff participation would have been partial or minimal, and that the system would consequently have been fraught with missing data. In an environment where organizational resources are limited and workloads are heavy, the value-added of the new system needed to be explained clearly and compellingly from the outset to justify the extra time and learning it required. Similarly, as the system developed, it remained important to include local personnel in decision-making, system refinement, process solutions, and implementation.

Involvement of the full range of stakeholders in system design and development was critical to user "buy in" and to the system's operational integration. The team initially comprised project leaders at Duke and Four Seasons but quickly expanded to include active participation of other partners. All staff, from mid-level providers and physicians who collect the data to senior leadership, were included in system development and implementation processes. At the project outset, the investigators identified an individual in a leadership position who could help advance the project internally; this nurse became part of a task force that worked with Duke staff to define core data elements and iteratively problem-solve. The project promoted teamwork on a daily basis, and through regular teleconferences and an annual workshop.

In preparing the Palliative Care Database to become a regional resource, it was critical to acknowledge and respond to local needs of subsequent sites. The three sites joining the Consortium in Year 2 shared an interest in data capacity to support quality reporting (e.g., PQRI). They, like many hospice and palliative care organizations, lacked high-quality, comprehensive, longitudinal data on their patients, services, and outcomes. Desire to collect data, learn from it, and benchmark their data against those of peer organizations motivated them to join the Consortium. This momentum was maintained through cultivation of a very collaborative relationship among sites. Bi-weekly teleconferences created a forum in which participants help each other interpret their data, share best practices, collaborate, and learn from one another.

Inclusion of metrics, reporting functions, and utilities that allow programs to derive higher reimbursement, improve care, and/or improve efficiency, such as the addition of the PQRI measures, will further incentivize these sites and likely motivate other organizations to adopt HIT-based data systems.

Technology must accommodate the needs and exigencies of the task, site, and user. Initially, the data-collection form was developed for real-time data collection, using a tablet computer at the bedside. This system failed to function smoothly due to connectivity issues and delays created in patient/provider communication (e.g., a pause required when moving from one data field to the next). Focus groups engaged users in problem-solving, but ultimately many providers opted to use the data-collection form in paper rather than electronic format, and the project team began exploring the electronic pen as an alternative platform.

Experience with tablet computers informed development of the electronic pen approach: efficiency was addressed up front by requiring providers to validate their data before downloading it; upon download, the system prompts for further input or correction if certain conditions are met (e.g., if a required field is blank). The electronic pens were programmed to store data from up to 20 encounters, to avoid interference with providers' workflow. Throughout process refinement, providers were shown how the HIT-based system could support better patient care.

Additional informative lessons emerged. Realistic appraisal of sites' HIT capacities is essential; where minimal HIT skills and resources are present, the most feasible approach may be a very simple system that leaves room for increased sophistication as the site's skills, resources, and interest permit. In implementing HIT-based data collection in a new site with no existing system, system design must be flexible. The platform and various process factors (e.g., timing of data transfer) may need to change based on the site's experience with implementation. Technical support and troubleshooting, particularly responsive customer support, is essential. Some hospice and palliative care organizations possess this expertise in-house, while others lack a well-developed IT department.

This project highlighted several ways in which a HIT-based data-collection system could benefit hospice and palliative care. Longitudinal data collection and warehousing builds durability of data, enables sites to benchmark their performance against others, and allows them to analyze their own performance over time. Standardization of data elements and data-related procedures, a requirement of HIT-based data collection, is

likely to improve data quality. Electronic methods streamline administrative functions such as collection of and reporting on quality data. As staff members become more fluent in data processes and facile with electronic data collection, the system evolves to become more sophisticated, and more data are added to the data set, the potential for in-depth exploration of quality and outcomes will increase.

The ability to query the growing database provides opportunities to identify and address issues and, over time, to examine how interventions improve care. Data can be analyzed by disease, demographics, socioeconomic factors, or patient-specific factors such as symptoms and performance status. Collection of longitudinal data allows for tracking of symptom burden over time, and quantifies the benefits of treatment interventions.[12] Establishment of electronic data processes prepares sites to participate in research, thereby helping build an evidence base for hospice and palliative care that includes community-based populations.

This project also illuminated challenges to the adoption of electronic data processes in palliative care. Many provider organizations are small and lack resources to devote to HIT; the expense of acquiring and implementing a new system will exclude these sites. Although pooling of resources may help overcome financial obstacles, collaboration among sites on organizational development concerns is not an historical norm.

Lack of awareness of the benefits of HIT for hospice and palliative care reduces motivation to explore HIT-based data practices. Many hospice and palliative care staff have limited numeracy skills, are not accustomed to working with data and valuing data-related processes, and possess minimal HIT background. Training and technical support will be crucial. For sites without background in research and data analytics, partnership with an academic medical center or other research institution can provide the necessary technical/analytic support. Demonstration projects that illustrate the benefits, and delineate the "how to," of HIT implementation in hospice and palliative care will prove highly instrumental to adoption. Next steps in the agenda for the Palliative Care Database project are presented in Table 2.

Interest in hospice and palliative care data is growing. In the past 3 months, over ten new potential partners have contacted the project leaders; each of these sites is considering participating in the Carolinas Consortium and Palliative Care Database at its own expense. In 2010, a national Palliative Care Research Cooperative Group was formed; the data infrastructure for this group will be harmonized with that of the Palliative Care Database to ensure interoperability of data.[13] And, in response to a growing recognition of

Table 2. Next steps in the Palliative Care Database project

Continuously upgrade the quality of the data being collected
Test reliability and validity of data elements, especially patient-reported data
Transition to more robust data elements as appropriate
Standardize recording (e.g., through manuals, videos, and education)
Institute quality assurance processes
Develop and implement standard operating procedures
Harmonize data elements with national standards (e.g., caBIG)
Update data elements to answer Consortium members' clinical questions
Develop a suite of data-collection platforms (e.g., tablet computers, electronic pens, other handheld devices, Internet), to offer options appropriate for the full range of clinical settings and patient types encountered in palliative care
Develop a modular implementation approach that allows smaller sites to begin collecting data in a limited way
Improve reporting functions
Design reports to meet the needs of clinical decision makers and palliative care program planners
Align quality reporting data infrastructure with research network (e.g., Palliative Care Database infrastructure with that of the newly formed Palliative Care Research Cooperative group through caBIG standards)
Develop patient-level reports so that the system facilitates care of the individual patient as well as aggregate analyses
Revise the database structure and data system to ensure data security as the system evolves, for example, as it becomes accessible over the Internet and includes a larger number of patients
Develop data-governance and data-stewardship plans
Initiate a workforce development plan that conjoins palliative care research, comparative effectiveness research, and HIT (e.g., an NIH K award program)
Conduct pilot projects that demonstrate how the data can be used in practice to support improvement in the quality of care and of research

caBIG, cancer Biomedical Informatics Grid

the need to define the value of palliative care, new projects are combining Medicare data for patients in the Palliative Care Database with quality measures.

Conclusion

Ultimately, data collection in palliative care may demonstrate the contributions of palliative care such as improved symptom management, assessment of psychosocial needs, completion of advance care planning, and reduction in costs of care. Collection of data across the continuum of care settings for patients with advanced disease will generate better understanding of these patients and their needs, and will support communication among providers. Aggregate data collection may support benchmarking and quality improvement efforts in hospice and palliative care, and hence may improve the quality of care. Analysis of data from large pools of patients will help identify trends in care and areas where improvements are needed. HIT approaches that can help the field progress include: academic/community partnership for data collection, management, and analysis; creation of multi-site, collaborative networks; use of various HIT platforms and strategies; and design of systems that meet needs identified by users and sites.

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