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Determining Community Provider Practices in Hospices: The Challenges of Documentation

Kimberly Bergen-Jackson, MSN, RN, BAGNC Scholar,
University of Iowa, Iowa City, IA

Sara Sanders, PhD, LMSW,
University of Iowa, Iowa City, IA

Keela Herr, PhD, RN, FAAN, AGSF,
University of Iowa, Iowa City, IA

Perry G. Fine, MD,
University of Utah, Salt Lake City, UT

Marita Titler, PhD, RN, FAAN,
University of Michigan, Ann Arbor, MI

Chris Forcucci, BSN, RN,
University of Iowa, Iowa City, IA

Jimmy Reyes, MSN, RN, BAGNC Scholar, and
University of Iowa, Iowa City, IA

Patricia McNichol, BSN, RN, CPHN
University of Iowa, Iowa City, IA

Abstract

Documentation is a key factor in supporting consistency and quality of patient care in the hospice setting, however variation among program provider practices, including documentation, were observed during the initial data collection phase of our National Cancer Institute (NCI) funded study, Cancer Pain in Elders: Promoting Evidence-Based Practices (EBPs) in Hospices. The study is a randomized trial to test a multifaceted intervention to promote adoption and maintenance of EBPs for cancer pain management involving 16 Midwestern hospices of varied size and structure. In the face of such variance, and especially in the absence of uniformly adopted outcome measures and documentation standards, quality improvement initiatives in this important and growing healthcare sector will be difficult to manage. This paper provides background on the importance of documentation, quality measures, outcomes of care, and regulatory imperatives in the hospice setting with specific observations from our research study and suggestions for changes in documentation practices.

From our observations, we posit the necessity of pertinent outcome measures supported by standardized documentation processes in hospice. Uniformity in key practice indicators and patient outcome measures in documentation systems would advance the movement to improve quality and consistency of care in hospices. Standardization of documentation systems and language would also facilitate the conduct of research in the hospice setting, a population for which advancing knowledge is essential to assure quality care at the end of life.

Keywords

Hospice; Documentation; Cancer Pain Management; End-of-Life; Evidence-Based Practices; Quality; Older Adult

Introduction

Federally mandated Conditions of Participation define the practice requirements for Medicare Certified Hospice programs, which serve over one million patients each year in the United States (1). There are, however no standards for clinical documentation, and no standardized metrics from which to assess or compare quality of care among hospice providers. Variation among program provider practices, including documentation, were observed during the initial data collection phase of our National Cancer Institute (NCI) funded study, *Cancer Pain in Elders: Promoting Evidence-Based Practices (EBPs) in Hospices*, a randomized trial to test a multifaceted intervention to promote adoption and maintenance of EBPs for cancer pain management. In the face of such variance, and especially in the absence of uniformly adopted outcome measures and documentation standards, quality improvement initiatives in this important and growing healthcare sector will be difficult to manage.

Using our experience in reviewing medical records from 16 Midwestern hospices of varied size and structure, we provide an overview of the challenges of documentation in the hospice setting and recommendations for facilitating quality documentation of provider practices and patient outcomes. From our observations, we posit the necessity of pertinent outcome measures supported by standardized documentation processes in hospice.

Background

Nurses are the largest group of healthcare professionals, playing key roles in the delivery of hospice care and quality initiatives (2,3). However, nursing practice remains largely invisible, partially due to inadequate documentation systems (4,5). Documentation of nursing practices is essential for knowledge development of nursing contributions to quality, patient safety, and patient outcomes (5–11). Furthermore, current public healthcare policies require documentation of nursing care, as well as interdisciplinary contributions, to demonstrate compliance with federal regulations (6,7, & 12). Perhaps most important, documentation is essential for continuity of care (5,7). Documentation provides a mechanism for understanding what treatments are working and what clinical problems are yet to be managed effectively. Without well-structured documentation, including outcomes of the overall plan of care, it is difficult to analyze or improve continuity of care delivered by different practitioners. Documentation of a large component of patient care practices is the responsibility of nurses, so the emphasis throughout this manuscript is on the documentation of nursing care specifically, although it is understood that other providers play a vital role in their contributions to the hospice patient care record.

Patient Records

The patient record provides authoritative information on patient care. Content highlights the care provided, assists with communication among providers in order to optimize coordination and continuity of care, supports reimbursement for services rendered, meets both governmental and accrediting agency regulations, provides evidence in a court of law, and generates data for research (13). Patient records are also commonly used as a data source for quality measurement and management.

While nurses acknowledge that documentation is important, the priority and focus in all settings has been on patient care first and documentation second (14). Nurses often state that “I did it; I just did not document it,” but regulatory and legal views on documentation counter with the often used adage “if it was not documented; it was not done.” The highest authoritative bodies (12) have underscored the need for complete, clear, and accurate health care documentation, as an essential element for the provision of quality patient care. For example, when comfort is a high priority, lack of documentation regarding pain treatment leaves the next practitioner with little information about the effects or problems associated with the prescribed analgesic for a given patient. Professionalism in healthcare requires that critically important practices and contributions to patient outcomes be documented in a patient record (5).

Standardized Documentation Systems

The development of a standardized documentation system is part of the intentional, and oftentimes third party payer-imposed, progression of healthcare organizational change and growth. The history of nursing homes and home care agencies provides a guide for the progression of the hospice industry. While the settings and philosophies of care differ among nursing homes, home care, and hospice agencies, the need to provide quality patient care and document it in a clear, concise manner is the same. Both nursing home and home care industries have adopted federally mandated reporting systems to assist with documentation of comprehensive assessment, outcomes measurement, and reimbursement.

The nursing home industry standardized the care plan process after OBRA 1987 legislation and the Minimum Data Set (MDS) provided the process for completing a comprehensive assessment of each resident’s functional status and identifying individual health problems. The information is entered and transmitted to state databases and captured by an established national database. This database has become the major standard assessment procedure for quality indicator data in the country (15).

Outcome and Assessment Information Set (OASIS) is a key component of the partnership between Medicare and the Home Care industry to foster and monitor improved home health care outcomes. Since 1999, OASIS has been the definitive and comprehensive assessment tool for outcome monitoring, clinical assessment, care planning, and reimbursement rates for home health agencies. OASIS forms the basis for both Outcome Based Quality Improvement (OBQI) programs and case mix adjustments under the home health prospective payment system (16). These systems may provide examples of positive and challenging aspects of standardized documentation systems to inform advancements in the hospice setting.

Quality Measures, Outcomes of Care and Regulatory Imperatives for Hospice

Over the last 30 years, the growth of Hospice care has been exponential. According to the National Hospice and Palliative Care Organization (NHPCO), in 2007 hospice providers served over 1.4 million individuals, or about half the people who died in the United States (1). Much of the growth in the hospice industry has been credited to the development of the Medicare Hospice Benefit in 1982 and greater attention within the medical community and society to the needs of those who are dying (17).

Overall, the growth of hospice can be viewed as a positive public health development, given the mounting evidence that quality, cost, and even longevity are positively impacted by early referral to hospice for those with end-stage diseases (17,18). However, this has created “growing pains” for the hospice industry as it faces greater scrutiny regarding quality and consistency of care, accountability for initial and continued eligibility determinations, and rapidly rising costs for professional services and palliative interventions, with reduced federal

reimbursement, similar to what other health care agencies, such as hospitals, home care programs, and nursing homes, have continually faced over the last 10–20 years (17).

As the Medicare Hospice Benefit evolves and fiscal intermediaries compete for contracts with the Centers for Medicare and Medicaid Services (CMS), hospices are spending greater time attending to regulatory issues (17) and justifying the terminal status of the patients in their program to ensure reimbursement. These challenges necessitate closer attention to the quality of patient documentation for patient care by hospice staff, particularly nurses.

Other than conventional standards for healthcare delivery, documentation of hospice care is motivated by payer source (e.g., CMS) or accreditation agencies (e.g., The Joint Commission). Since the majority of hospice patients are Medicare Part A beneficiaries covered under the Medicare Hospice Benefit, documentation is largely driven by the Medicare Conditions of Participation for Hospice Care under the Code of Federal Regulations, Title 42, and Part 418 (42CFR418).

In the Conditions of Participation, the need for documentation is implicit, both for compliance purposes (i.e., maintenance of certification under Medicare) and for payment by Medicare fiscal intermediaries (19). However, there is no standard format established, nor detail provided, other than in a few sections that explicitly refer to documentation, most notably pertaining to election of the benefit, certification of eligibility, and establishing the plan of care. From a Quality and Performance Improvement (QAPI) perspective, a focus on the plan of care is particularly important, although again, there are no set standards, formats, or specific requirements. Section 418.55 states that a written plan of care must be established and maintained for each individual admitted to a hospice program, and the care provided to an individual must be in accordance with the plan. There are three components to this: a) establishment of a plan by the attending physician, medical director or designee and the interdisciplinary group; b) the plan must be reviewed regularly and documented; c) content of the plan is based upon individual needs assessment, identification of services including management of discomfort, symptom relief, and scope and frequency of services to meet the patient's and family's needs.

In addition, Section 418.66 identifies quality assurance as a required condition, stating that a hospice must conduct an ongoing comprehensive, integrated, self-assessment of the quality and appropriateness of care provided. Notwithstanding the fact that there are no details to inform the process by which hospice programs should proceed in its day-to-day operations to measure outcomes of care, explicit reference to "discomfort and symptom relief" in requirements for the plan of care suggests a logical starting point for quality measures in hospice. This theme is central to measures elaborated several years ago by NHPCO, which include self-determined life closure, safe and comfortable dying, and effective bereavement as key end outcomes of quality care.

Within CMS, there is a strong and deliberate drive to establish quality measures and performance standards as a means to compare all Medicare programs, including hospice (20). A means to this end is through contracting with Quality Improvement Organizations (QIOs) to define quality indicators and implement processes to measure outcomes (21). Under the direction of CMS, the QIO Program consists of a national network of 53 QIOs, responsible for each U.S. state, territory, and the District of Columbia. QIOs work with consumers and physicians, hospitals, and other caregivers to refine care delivery systems to make sure patients get the right care at the right time, particularly patients from underserved populations. The Program also safeguards the integrity of the Medicare Trust Fund by ensuring that payment is made only for medically necessary services, and investigates beneficiary complaints about quality of care. To achieve the vision of the QIO Program, *"the right care for every person*

every time,” the Program assists providers in transforming care delivery to meet the National Academy of Science’s Institute of Medicine (IOM) goals, that healthcare be safe, effective, patient-centered, timely, efficient, and equitable (22).

It can be reasonably concluded that the call for standardized process and outcome measures, and evaluation of processes of care that lead to defined desirable outcomes in hospice, will accelerate. Electronic information management systems, including documentation, will be required to meet this demand. With these imperatives, hospice programs are encouraged to evaluate their administrative and clinical processes and procedures, develop a strategic plan to upgrade their systems so that they have the capacity to input and analyze quality measures, participate in local, regional or national quality initiatives, and (if not already in place) commence and document QAPI activities.

Documentation in hospice

Risk management has become a key motivation for accurate and detailed healthcare documentation (23,24). However, from the perspective of what matters most to patients and their families facing end-of-life issues, accurate and detailed documentation must reflect their most pressing needs, which in turn should foster good care (25). In hospice, which uses an interdisciplinary model, detailed documentation facilitates communication and collaboration among team members who provide care to patients and families. Although the incidence of medical errors in this setting is unknown, clear, complete, but concise and accessible documentation may be one factor to reduce medical errors (12,26).

The nature of hospice care presents inherent challenges to detailed and accurate documentation for nurses. For instance, hospice nurses mostly manage caseloads of patients who reside in their own homes, many of whom have complex healthcare issues and challenging social situations. As nurses strive to meet the needs of each of their patients, some of whom are in crisis, a highly efficient and effective contemporaneous documentation system is needed. A common perception among nurses is that time spent documenting detracts from sufficient time with the patient and family, which many see as one of the hallmark features of hospice care. Therefore, any documentation system must be efficient and nurses need to be convinced of the value of maintaining a good record of their work. It can also be argued that employees who do not appreciate the value of good documentation or do not complete their records in a timely manner are, by definition, not living up to professional standards.

Other challenges to documentation relate to the communication patterns of professionals in hospice programs. While hospice programs are mandated to have regular interdisciplinary team meetings (27), informal communication about patient needs is common. Informal communication via voice mail, phone calls, and “hallway discussions” occur and patient care decisions and changes in treatment are made during these discussions, which often go undocumented. This requires due attention and ongoing vigilance to ensure that changes in patient status and the care plan are charted.

The drive to move from traditional paper to electronic medical records (e-MR) has presented additional challenges to hospices. As hospices change systems of documentation, more frequently nurses are asked to carry laptop computers into the field with the intent of improving documentation. However, current electronic systems are often plagued with issues related to content and process, and detailed documentation of the most meaningful aspects of care delivered is often not feasible.

Issues related to pain documentation influencing practice and quality

Our NCI funded study focuses on facilitating Evidence-Based Practices (EBPs) specifically related to cancer pain management practices in older adults receiving care in home hospices. Evidence of provider pain practices were identified through abstraction of medical records of eligible patients for the first two weeks after hospice admission to one of 16 hospices (small, medium, and large) in the Midwest. Although we focused only on pain practices, the issues identified would apply to documentation of other health provider practices in caring for persons at the end of life.

A challenge to the abstractors was the diverse recording structures used across providers and hospices, which necessitated careful review of all documentation available to identify evidence of specific provider practices. Paper documentation and narrative notes were common, although some facilities were developing or had partial electronic documentation systems.

During data abstraction and interpretation of pain practices, we noted documentation inconsistencies that were similar to those identified in like studies (28,29). Specifically, the notes revealed inconsistencies regarding documentation of regular pain assessment, use of a validated pain scale, and the recording of responses to treatment over time. For example, in the current study and the Gunhardsson study (28), researchers noted that pain was documented, as “the same as yesterday” with no documentation from the day before or there was documentation of current pain with no documentation of any follow up.

The current state of hospice documentation that we observed is not necessarily correlated with interest level, seriousness of purpose, or capabilities of the nursing staff (or other interdisciplinary team members). Rather, documentation patterns and practices evolve out of informal communication patterns and inadequate hospice specific documentation systems. For example, some of the software programs and systems utilized by hospice nurses were not created exclusively for hospice, but were developed in home care, which has different priorities, methods, and ideologies. These software programs and systems may be inadequate for charting specific information for hospice patients or may lack in-depth pain-related questions, treatment preferences, management modalities, and other (but often related) symptom management concerns such as fatigue, depressed mood, sleep disturbance, nausea, vomiting, constipation, and diarrhea. In our study, we found that clinically relevant text fields were not always available in e-MR or nurses had to scroll through many contextually irrelevant “pages” to complete the documentation. Electronic documentation alone without efficient underlying documentation processes and careful design of applications will not achieve better documentation of care delivered (12). Software programs intended for hospice use must be created, tested, and implemented with hospice-specific quality measures and outcomes in mind. To be effective, these systems must be designed so that charting detailed questions regarding pain and other key symptoms and quality measures can be captured and entered into a relational database in real-time. The software should be designed with consideration of the workflow of nurses in this setting. Ideally, nursing staff should have the means of providing constructive feedback about the systems themselves so that improvements can be made.

A universal challenge is efficient use of nursing staff time during the charting process and data entry. Contemporaneous charting of key variables can never be viewed as “optional,” but rather a professional duty. Adherence to this imperative is a function of leadership within the hospice program/organization. Commitment to fastidious documentation practices becomes a quality measure that must be taught, audited, and reinforced on a regular basis so staff have total “buy in” to this critical dimension of hospice care. Therefore organizational commitment to the provision of sufficient resources (staff time) to accomplish effective care documentation is

necessary and nursing staff must be provided with feedback about the outcomes of their efforts to create positive reinforcement for their efforts.

Another documentation challenge that we identified is the misuse and under-utilization of common terminology or tools (specifically related to pain as the focus of our study). Hospice nurses did not use a common language or tools when describing patients' pain complaints and other symptom complexes. In one example, nurses used different tools to measure pain intensity on the same patient. One selected a numeric rating scale while another chose the PAINAD scale. Both tools resulted in a numerical rating associated with pain, but the ratings were very different. In another example, one nurse documented, "patient denies pain" and "patient unresponsive" in the same pain assessment. Variation in language and utilization of tools affects the quality, consistency, and *depth* of charting, as well as communication among care providers and settings, and the potential diagnostic value of pain and symptom assessment. Variable, inconsistent, or non-specific terminology among nurses' notes was found in the breadth and depth of pain assessment, treatment plans, patient education, and follow-up details that were recorded. For example, in referencing to pain patterns, different terms were used when talking about the same things, where one nurse refers to "severe abdominal pain" another refers to "cramps." Some charts used a checklist detailing specific content where others presented information in a narrative format when the task was completed. The findings from our chart reviews suggest several key issues related to documentation in this group of hospices that may influence quality of pain care and management of other important symptoms at the end of life.

Potential impact on research

Documentation of health care provider practices and patient and family outcomes is not only critical for promoting high quality care delivery, but can have a major impact on the conduct of research in this practice setting. Of the many exigent challenges to research in the hospice setting, mostly due to the short life expectancy of most patients, documentation is one area that does not fall prey to the many clinical and ethical confounds of this healthcare domain. For some research questions, and particularly when working with the end-of-life (EOL) population, it is not always possible or feasible to conduct a tightly controlled, blinded, randomized prospective analysis of specific interventions on outcomes. It is for this reason that medical record abstraction is a necessary data collection approach. In order for record abstraction to be feasible, no less meaningful, the records themselves must be cogent and coherent.

Data abstraction in our study was impacted by the diversity of documentation approaches both within and across hospice programs. The approaches to documentation varied from all narrative documentation, to partial checklists and narrative, to complete e-MR use. Because of the complexity of the provider practices of interest in our study, considerable time was devoted early on to determining where and how to identify indicators of key practices, how to reliably interpret narrative and electronic notes regarding practices, and how to interpret lack of documented practices. Increased time to abstract records, increased numbers of research assistants (RAs) to provide double record abstraction, additional time to conduct data cleaning of all variables, and adjudication of any discrepancies between abstractors (all necessary to assure reliable data) contributed to increased costs and delayed timely research progress. For example, the mean time for both abstractors to review one record, clean the data, and adjudicate any discrepancies in our study was four hours. This was almost three times the original time budgeted in the grant. Greater efficiency resulting in marked research cost savings and accuracy can be gained through standardized documentation of the most relevant clinical indicators, such as pain and pain practices. Until such process improvements are made, it is important that researchers and funders understand these factors in planning the design, timeline and budget for research in this setting.

Suggestions for documentation approaches

In an effort to improve consistency and quality of care, individual hospice providers can change documentation practices in several ways. Identification of key assessment and treatment practices that should be documented is a necessary first step. This should include determining an organizational standard for use of valid, culturally sensitive assessment scales. Developing documentation strategies that incorporate patient goals is also needed. Staff education on use of selected scales and documentation expectations that includes opportunity for discussion of challenges to effective documentation, as well as the importance of quality documentation practices. Improved documentation practices are most likely to occur if staff members are involved in developing documentation tools and procedures. It is critical for nursing to assume leadership and responsibility for the standards of their profession in documentation as well as care.

A new framework for guiding development and testing of electronic health records, such as providing family members access to the electronic health record to document symptoms and medications, may be needed. Although novel health information technology (HIT) innovations are in development and used in other health care settings, the most effective model for the hospice setting is yet to be determined. One consideration to advance consistent documentation of nursing practices, particularly nursing interventions and outcomes, is the incorporation of standardized nursing languages into documentation systems. Nursing Interventions Classification (NIC) and Nursing Sensitive Outcomes Classification (NOC) (30) are two examples of nursing languages that have been incorporated into Systematized Nomenclature of Medicine (SNOMED) as well as integrated into software supported by national vendors. The value of NIC and NOC has been established for a variety of specialty practices; including Hospice, and contains core outcomes under End of Life for NIC and for Hospice and Palliative Care for NOC (31,32, and 33). Other nursing languages are also available and may be relevant for this setting such as the Omaha Classification System (34).

It would be highly constructive at this time for hospice organizational leadership (e.g., a collaborative effort among NHPCO, the American Academy of Hospice and Palliative Medicine, and the Hospice and Palliative Nurses Association) to appoint a task force to work with CMS to design and test a documentation system specifically for hospice settings. Second-phase demonstration projects such as this are long overdue insofar as the Medicare Hospice Benefit is now more than 25 years old and there have been considerable advances both in systems and in clinical technologies during this time. Agreed upon documentation elements could then be incorporated into existing and new electronic records so that the required data elements can be efficiently and effectively extracted to calculate the required quality metrics.

Lastly, we suggest a need for competitive HIT studies supported through the usual publically funded granting agencies to develop and test electronic health records for the hospice setting. Advancements in HIT would facilitate the means by which a myriad of other research questions related to the quality of patient care and impact of interventions on patient outcomes are answered.

Summary

Observations on the importance and challenges of documentation, necessary to support consistency and quality of patient care in the hospice setting have been highlighted, including challenges identified in our research experience in 16 Midwest hospices. Although our findings may not reflect documentation practices in hospices in other areas of the country, we do conclude that uniformity in key practice indicators and patient outcome measures in documentation systems would advance the movement to improve quality and consistency of care in all hospices. Standardization of documentation systems and language would also

facilitate the conduct of research in the hospice setting, a population for which advancing knowledge is essential to assure quality care at the end of life.

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