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Advanced Disease Management in Home Healthcare: Palliative Care Integration

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Abstract

With home health caring for patients with serious illnesses and advancing disease states, palliative care in a community setting like the home, can provide many benefits. This population currently has a gap in the healthcare continuum at the point of advancing disease state to end of life care. Recently, new payment models based around clinical outcomes, including hospitalization scores and quality indicators, has caused home health to explore different ways to deliver quality and effective care, especially for those with the highest risk of hospitalization. A literature review was conducted to identify benefits of palliative care integration within home health which revealed improved symptom management, communication around goals of care, end of life and hospice determinations and reduced costs for unnecessary healthcare use. A gap analysis was completed by reviewing the national standards for palliative care and the organizations' current traditional home health care to determine those gaps in care. Using the evidence-based literature and clinical guidelines, a project was designed to fill the gaps through training and intervention strategies. This project evaluated the training and intervention strategies for home health patients with advanced disease states. Outcomes included learning during project implementation, evaluation of intervention tools, and aggregate hospitalization and improvement in pain scores. Results showed a benefit in the reduction of hospitalization scores and an increase in improvement in pain scores within home health compare results, and significant t-test results related to palliative care needs using a symptom management tool.

Background and Significance

A Gap in Care

As the population in the United States has aged, the number of people living longer with multiple chronic diseases or conditions has increased. Chronic diseases and conditions are the leading cause of death and disability in the United States (National Center for Chronic Disease Prevention and Health Promotion, 2016). Greater than 80% of Americans 65 and over live with multiple chronic conditions (Gerteis et al., 2014). Thirty five percent of healthcare spending is for the 8.7% of people with five or more chronic conditions (Gerteis, 2014). The Agency for Healthcare Research and Quality (AHRQ) noted that the prevalence of multiple chronic conditions increases dramatically with age (Gerteis, 2014).

Home health care provides skilled services to patients who need care in the home. Organizational data through Strategic Health Programs ([SHP] https://www.shpdata.com) showed most home health patients have a chronic illness such as Congestive Heart Failure (CHF) and Chronic Obstructive Pulmonary Disease (COPD) or receive skilled therapy for treatment of a musculoskeletal illness or injury, usually from a chronic disease like osteoarthritis (www.shpdata.com). Traditional home health care provides skilled care to stabilize an exacerbation or onset of a disease process, many times following a hospital or short term rehabilitation facility stay. This care is typically planned to accomplish short term goals that fit within Medicare's 60 day window of reimbursement and prepare the patient for discharge back to the community.

With the aging population, the advancing chronic illnesses, and the rising costs of healthcare, healthcare providers are evaluating current care models for necessary changes. As a healthcare system, providers are becoming more collaborative to improve communication and decrease unnecessary healthcare costs. Evidence-based practice guidelines and some payment structures are being examined to address gaps in care.

Palliative care is care for people with serious or advanced illness with a focus on providing relief of symptoms and stress of a serious illness, regardless of the diagnosis (Center to Advance Palliative Care [CAPC], 2017). While this definition of palliative care includes all diagnoses, the progression of chronic disease in the aging population has created a gap in home health care delivery. A review of the literature produced evidence of the need for the layering of palliative care principles on traditional home health care to improve multiple key metrics for those patients with advancing disease states. National standards for a comprehensive palliative care model were identified to guide the review of current organizational processes and procedures, to identify key gaps, and to create comprehensive care delivery. Gaps were identified related to assessment and communication of symptom management, communication with patients, families, and the healthcare team around goals of care, spiritual assessment and resources, and implementation of advanced care planning. Interventions of advanced care planning, communication about disease progression at end of life, and end stage symptom management are not generally included in most home health agency practices. Addressing this gap in delivery is an opportunity for patients, healthcare providers and payers to benefit through improved quality of life and effective use of healthcare resources, while allowing patients to receive care in their own home.

Purpose Statement

The purpose of this project was to implement evidence-based palliative home care interventions for patients with advanced disease, with the goal of improving patient outcomes and reducing hospitalizations.

Review of Current Home Healthcare

The home health benefit provided by Medicare covers a 60 day episode of care with specific coverage criteria regarding skilled care provided by nursing and other disciplines (CMS, 2008). The plan of care is focused on stabilizing the patient from an acute onset or exacerbation of a disease process. Five criteria must be met for home health services to be reimbursed by Medicare. Patients must be homebound and require skilled services (as defined by Medicare) on a part-time intermittent basis. The service must be reasonable and necessary and provided under a plan of care (CMS, 2008). Skilled nursing care includes observation and assessment, teaching and training, treatments and procedures, and management and evaluation of a client care plan for non-skilled care needs. Skilled care by physical, occupational, or speech therapists for a new or exacerbated diagnosis must be necessary to improve functioning or be deemed necessary to decelerate or prevent further deterioration of the patient's condition (CMS, 2014).

Payment for home health for a 60 day episode is similar to hospital reimbursement for a Diagnosis Resource Group (DRG). A home health resource group (HHRG) is paid for a 60 day plan of care based on multiple factors from the initial assessment and patient care plan. Frequency and duration of visits are managed by home health organizations while also considering efficiency and cost-effectiveness. While home health currently is not subject to any rehospitalization penalties, value based purchasing (VBP) for home health agencies and bundle payment reimbursement models are coming into existence (https://innovation.cms.gov/initiatives/home-health-value-based-purchasing-model). Within these new reimbursement models, metrics affecting patient outcomes and cost containment will become a fiscal issue for the organization. Adding palliative care interventions over the traditional home health skilled service delivery has the potential to provide a more comprehensive approach to patient care while also helping to ensure fiscal viability of the organization.

Review of the Literature

A literature review from the past ten years was conducted with evidence ranging from meta-analyses to peer-reviewed organization standards. Studies in the last ten years were used due to the low volume of research in palliative care in the home and community setting for non-cancer patients. While some of the literature included those patients with cancer, other studies were eliminated that were dedicated to palliative care specifically for cancer patients. The American Association of Critical-Care Nurses (AACN) levels of evidence (Peterson et al., 2014) was used to evaluate the evidence.

A literature review was previously published related to palliative care for serious illness or advanced disease in home health care (Stober, 2017). The evidence showed that palliative care in the home health setting has clear benefit for the patients with serious illness through improved symptom management, decreased utilization of healthcare resources and costs of care, improved communication with established goals of care, and improved end of life disposition. Within the review Stober identified a meta-analysis by Gomez et al. (2013) from the Cochrane Library Review. Outcomes were reported related to death at home, symptom burden, pain management, physical functioning, quality of life, caregiver burden and grief, and satisfaction with care. The population included adult patients with malignant and non-malignant disease, with the majority of patients being those with cancer. With this meta-analysis having limited research on the non-cancerous population, the review appears to identify the gap in palliative care literature for patients in the community with advanced chronic disease, and specifically home health. In addition, the review also supports the evidence reviewed by Stober, with the exception of financial cost savings in patients with non-cancerous disease (Gomez et al., 2013).

Symptom Management

There are multiple symptoms to be managed for patients with advanced disease. Kelly and Morrison (2015) identified the following key symptoms of the seriously ill that require palliative care management: anorexia, anxiety, constipation, depression, delirium, dyspnea, nausea, and fatigue. In non-cancerous diagnoses like COPD and CHF, the symptoms of anxiety, dyspnea and fatigue were more prominent. Kelly and Morrison also found that a comprehensive symptom assessment set, using a validated instrument, is needed. Stober previously found the use of Edmonton System Assessment System (ESAS) (www.npcrc.org) as one of the validated tools reported in the literature (Bruera et al., 1991; Ferrell &Coyle, 2014; Ornstein et al., 2013). While the ESAS was developed for cancer patients, this tool is recognized for use with any type of patient with palliative care needs (Richardson & Jones, 2009). The tool is recommended to be completed on a regular basis (daily or weekly depending on the care setting), and then trended on a graph for determination of symptom exacerbation.

In the work by Stober (2017), two additional studies incorporating palliative care into home care reported significant improvement in symptom management (McCall et al., 2008; Ornstein et al., 2013). Consistent use of a validated tool to track changes in key symptoms is not currently done in standard home health nursing documentation. Use of a validated tool to track data over time can identify incremental disease progress and be used to address needed changes to the plan of care. This can improve symptom management.

Decreased Utilization and Costs of Care

Stober (2017) previously noted the economic savings of eliminating avoidable hospitalization and ER visits. Decreasing wasteful healthcare dollars is a topic of particular interest for hospitals with multiple reimbursement penalties or bundled payment savings. Cassel et al. (2016) studied the nonclinical outcomes of a palliative care program funded by a Medicare Advantage plan for patients with cancer, heart failure, COPD, and dementia. The majority of patients had a non-cancerous advanced disease state, similar to the patients in the current project. The researchers concluded that palliative care was successful in avoiding hospital costs when the alternative payment model created risk for the provider. Quality data were not reviewed.

Stober found other studies to support decreased costs (Brumley et al., 2007; Chen et al., 2015; Ranganathan, Dougherty, Waite, & Casarett, 2013). These studies showed significant decrease in at least one of the two costly healthcare resources, ER visits and hospitalizations. A decrease in any unnecessary healthcare resource calculates to lower costs of care.

Communication and Goals of Care

Stober identified studies about communication between the home health staff and the patient and family (Brumley et al., 2007; McCall et al., 2008; Reinke et al., 2008; Stajduhar et al., 2010). Each study identified the relationship of the home health staff with the patient and family to be foundational for optimal communication about prognosis, disease progression, and goals of care. Norton et al. (2013) identified prognostic communication as a primary component in an effective palliative care model. Stober noted that a broad base of outcomes is facilitated through communication and development of a collaborative plan of care with the patient, family, and health care providers. Home health creates an environment for such communication.

Advanced care planning is one of the goals of this communication. The majority of patients with serious illness are interested in communication about disease progression and options for treatment, including the option of eventually receiving end of life care at home (CAPC, 2011; Gomez et al, 2013). The home health staff can assist the patient in understanding the typical disease progression and develop a plan of care centered on their values and wishes.

Quantifying those individuals who want to choose hospice yet are never given the choice is difficult. However, only about half of those patients who do utilize the hospice benefit option survive more than 14 days (The Hospice Action Network, 2013). This data support the need to better communicate with patients and families regarding disease progression and options for goals of care. Communication about values, goals, and advanced care planning are paramount to creating an end of life journey that honors patient wishes.

End of Life Disposition

The themes of communication, goals of care, and end of life are inter-connected. Patients want to know about choices, want to be involved in goals of care, and most want to die at home. Cassel et al. (2016) found that 87% of patients in the palliative care model received hospice care. While all outcomes studied were around healthcare resource use and cost, the obvious increased use of hospice becomes a quality measure in itself.

Kelly and Morrison (2015), in a review of palliative care in all settings, saw an increased focus on communication skills and tools to assist clinicians in having difficult conversations, including a discussion of disease progression and end of life decisions. Results included increased use of hospice and improved family satisfaction with end of life care. The researchers found multiple tools and road maps to guide clinicians through the communication process that would lead to advanced care planning.

Making sure the wishes of the patient are clearly understood is an important component of creating care goals and advanced care planning. Conversations need to occur early when patients are able to communicate their own needs. The patient with dementia creates additional difficulties due to changing cognitive status. Patient wishes cannot be ascertained once communication skills have been severely compromised by dementia. Dempsey, Dowling, Larkin and Murphy (2015) found this population is not receiving adequate palliative and end of life care because of a lack of adequate staff education of palliative needs in this population.

Stober noted support for the use of palliative care in the disposition of end of life decisions through advanced planning and transition to the hospice benefit. The National Consensus Project for Quality Palliative Care (2013) and the CAPC training materials list advanced care planning as a key component of the clinical guidelines. End of life discussions should include understanding the patient’s vision of a peaceful death, including when to discontinue curative care and shift to palliative care only. These kinds of conversations require a relationship between the clinician and the patient and their caregivers, which is more likely to develop in the home health setting than in a facility. Because home health provides care to a patient over an extended period of time, development of a relationship between the clinician and the patient or family often occurs, and may facilitate these types of conversations.

Current Practices and Innovations

Although reimbursement has not changed for traditional home health since the inception of episodic payment methodology around the turn of the century, there are pockets of alternate payment structures and pilot projects interested in finding solutions for patients with advanced illness and disease. Distinct innovative programs targeting patients with advanced illnesses have highlighted the use of palliative care interventions within traditional home health care services (Labson et al., 2013; Thompson, 2017). An Advanced Illness Program pilot at Fidelity Health Care showed cost of care cut in half for those patients enrolled (Thompson, 2017). Kaiser Permanente found multiple positive outcomes for both the patient and the healthcare system including higher satisfaction with care, increased likelihood to die at home, and decreased metrics of hospitalization, ER use and overall costs of care (Brumley, Enguidanow, & Cherin, 2002). This study was completed by an entity interested in identifying cost savings while improving outcomes nearly fifteen years ago, and yet traditional home health care across the country within the Medicare payment system has not had any policy discussions on adding these guidelines into its delivery or payment model. One cause may be that payment models are segregated according to service provider. CMS is developing new reimbursement structures such as 30 day rehospitalization penalties, and bundled billing models to focus all healthcare providers on outcomes that span the patient care continuum.

With current trends related to achieving quality outcomes and reducing cost of care across the healthcare continuum, palliative care seems to be an obvious component of home health clinical protocols and guidelines. An additional incentive for home health agencies and other health care providers is the implementation of the Improving Medicare Post-Acute Care

Transformation Act (IMPACT, 2014). This CMS regulation set into motion public reporting of patient outcomes and quality measures for skilled care, rehabilitation, and home health care agencies. This reporting evolved into publicly available aggregated outcomes related to patient care. In addition, as hospitals look for solutions to the current penalties on key diagnosis readmission scores, they have uncovered home health as a key component to reducing 30 day rehospitalizations (Labson, 2015). The use of palliative care in the home health sector has shown to be effective in decreasing hospitalizations and other healthcare costs and could be a way to continue collaboration across the care continuum while providing positive outcomes to all stakeholders.

An innovation project by CMS is underway to initiate hospice coverage while curative care continues (https://innovation.cms.gov/initiatives/Medicare-Care-Choices/). This project is only available in small pockets across the United States. Home health can bridge the gap by integrating palliative care services with traditional home health under the existing home health reimbursement model. This integrated model can identify skilled home health needs that may otherwise be overlooked without additional palliative care training and tools.

Implications for Stakeholders

In the healthcare system, there are multiple stakeholders with the patient as the ultimate stakeholder. The patient with an advanced disease relies on the healthcare system to provide information and navigation of healthcare to achieve the best possible health status throughout the disease process. Other stakeholders include employees, referral sources (hospitals, facility staff, physicians, and families), payers, and the community. Depending on the type of healthcare organization, stakeholders might also include the board of directors or its stock holders. The healthcare organization itself is a stakeholder for viability reasons. Since federal funds support the Medicare and Medicaid programs, the entire system is a stakeholder.

The referral sources are interested in both the clinical outcomes of the patient and financial outcomes of their organization. While hospitals are currently and primarily interested in 30-day rehospitalization scores, this interest will likely be extended beyond the 30-day period as new payment models are implemented. Home care organizations share an obligation to partner with both referral sources and payers as new payment models arise. There are multiple payment models introduced by the Centers for Medicare and Medicaid Services (CMS) related to bundled billing (https://www.inovation.cms.gov, 2016). Kelly and Meier (2015) note current and potential innovations in Medicare Advantage plans regarding palliative care in the Medicare population which can affect quality while lowering cost. These payment models have created incentives for healthcare organizations to take innovative risks which are resulting in improved quality measures through the development of additional practice guidelines and interventions. As these models and payment incentives are implemented, home health organizations have an opportunity to be leaders in the development and integration of new palliative care interventions for those patients at home.

These new models need to focus on evidence-based standards to provide optimal patient outcomes, quality of life, and efficient use of healthcare dollars. Training and certification in palliative care is available through many avenues including national organizations like the Center to Advance Palliative Care which has a full training curriculum. Research shows that education and training related to palliative care improves patient satisfaction, as well as nursing skills and confidence of staff (Brumley et al., 2007; Wilkinson, Perry, Blanchard, & Lindsell, 2008).

All stakeholders have an opportunity to benefit from the implementation of evidence-based palliative care guidelines. Palliative care guidelines should be an additional layer within the current traditional home health practice, especially for those with advanced disease. As seen in the review of the literature more research is needed regarding palliative care in home health, especially related to patients with advanced non-cancer illness and disease. The current evidence does show potential for benefits both clinically and financially through improved symptom management, communication around goals of care, and advanced care planning, leading to more efficient use of healthcare dollars and a more peaceful death experience.

Conceptual Framework

The Comfort Theory

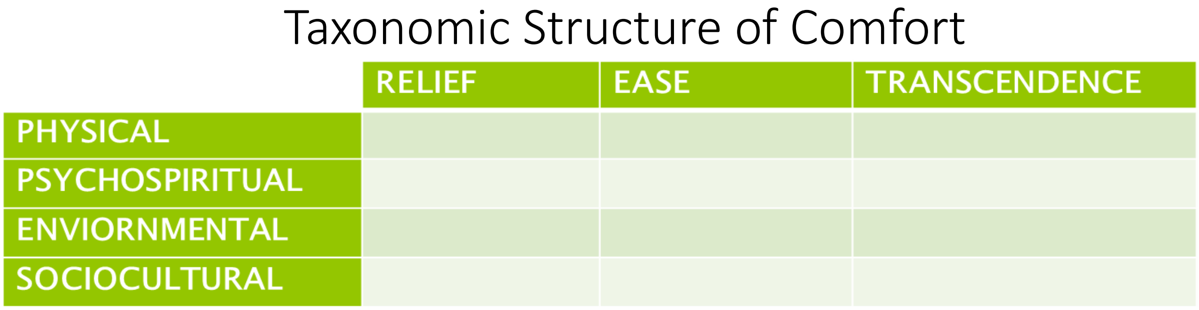
The Comfort Theory by Katharine Kolcaba (1991) provides an excellent foundation for clinical practice for advanced disease management in home health. The theoretical framework identifies the concepts defined by Kolcaba (see figure 1) as health care needs, nursing interventions, intervening variables, health seeking behaviors, and institutional integrity (http://thecomfortline.com/home/intro.html). These concepts are found in the theoretical definition of comfort as those immediate experiences that strengthen the patient who is having needs met for relief, ease, and transcendence of symptoms in the physical, psychospiritual, sociocultural, and environmental contexts (see figure 2).

Figure 1

(http://thecomfortline.com/home/intro.html)

While comfort may be an intervention by the home care nurse to eliminate or lessen symptoms, comfort is not simply symptom relief. The taxonomy structure is a grid of the defining attributes of comfort within the theory. Patients with advanced disease are likely living with multiple chronic illnesses and many are nearing end of life. The comfort theory allows for meeting the need for ease and relief of symptoms and also transcendence, or rising above the problem or symptom, ultimately choosing a peaceful death experience.

Figure 2



Taxonomic Structure of Comfort

	RELIEF	EASE	TRANSCENDENCE
PHYSICAL			
PSYCHOSPIRITUAL			
ENVIORNMENTAL			
SOCIOCULTURAL			

Adapted from “Middle Range Theories: Application to Nursing Research,” by S. Peterson and T. Bredow, 2013, p. 196. Copyrighted 2013 by Wolters Kluwer Health; Lippincott Williams &Williams.

This project finds itself submerged in the Comfort Theory. The patient needs for comfort are identified through the home health assessment process. The interventions are multi-disciplinary. The institutional mission of the home health organization involved in this project, making lives better through home care, is congruent with this theory. The purpose statement of this project includes enhanced comfort through fewer hospital visits, and improved quality of life.

Current Clinical Practices and Guidelines

Clinical guidelines were a foundation for any model reviewed in the literature. Many of these cited the National Consensus Project ([NCP], 2013). The CAPC, the American Academy of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association, and the National Hospice and Palliative Care Organization are four national consortium organizations focused on palliative and hospice care. Each participated in the National Consensus Project for Quality Palliative Care which resulted in the creation of Clinical Practice Guidelines for Quality Palliative Care. In the National Consensus Project, four models of palliative care are described: hospice, institutional based programs, outpatient programs, and community programs. Home health is a subset of the last one (National Consensus Project for Quality Palliative Care, 2013).

The NCP identified eleven key elements of palliative care: patient population, patient and family centered care, timing of palliative care, comprehensive care, interdisciplinary care team, attention to relief of suffering, communication skills, skill in care of the dying and the bereaved, continuity of care across settings, equitable access, quality assessment and performance improvement (National Consensus Project for Quality Palliative Care, 2013). These key elements are embedded in the eight domains of palliative care clinical practice guidelines:

structure and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious and existential aspects of care; cultural aspects of care; care of the imminently dying patient; and ethical and legal aspects of care. A gap analysis was completed (see Figure 3) to identify areas in current practice for the home health organization used in this project that need to be addressed to create comprehensive home health care for patients with advancing disease states.

A decision was made to not include the key element of care of the imminently dying, but rather to include appropriate transition to hospice when possible as one of the goals of this project. Between the key elements and the clinical guidelines, it was determined that the gaps in care were related to:

- Overall understanding of palliative care and how to implement in home health
- Communication around goals of care, disease progression, and advanced care planning, including hospice readiness assessment
- Symptom assessment and management
- Spiritual, religious, and existential aspects of care.

Figure 3

GAP ANALYSIS OF NATIONAL CONSENSUS PROJECT ELEMENTS and GUIDELINES IN TRADITIONAL HOME HEALTH CARE DELIVERY

Key Elements	**Traditional Home Health Care**
Patient Population	Exists
Patient and Family Centered Care	Exists
Timing of Palliative Care	*GAP*
Comprehensive Care	*GAP*
Interdisciplinary Team	Met
Attention to Relief of Suffering	*Partial Gap*
Communication Skills	*Partial Gap*
Skill in the Care of the Dying and the Bereaved	HOSPICE ONLY
Continuity of Care across the Settings	*Partial Gap*
Equitable Access	Exists
Quality Assessment and Performance Improvement	Exists

Clinical Practice Guidelines For Quality Palliative Care	**Traditional Home Health Care**
Structure and Processes of Care	*Gap*
Physical Aspects of Care	*Gap*
Psychological and Psychiatric Aspects of Care	Exists
Social Aspects of Care	Exists
Spiritual, Religious and Existential Aspects of Care	*Gap*
Cultural Aspects of Care	Exists
Care of the Imminently Dying Patient	HOSPICE
Ethical and Legal Aspects of Care	Exists

(www.nationalconsenproject.org)

Methods

Design

This project involved the development of a set of training sessions and assessment/intervention tools that incorporate palliative care concepts for home health patients with an advanced disease. The design was pre-test/post-test, examining patient and agency outcomes before and after initial implementation of the project interventions.

Setting

This project took place in eight locations within two home health agencies in Kentucky, both of which are subsidiaries of Almost Family, Inc. The home health organization is a national home care company with hundreds of locations in dozens of states, including Kentucky (http://almostfamily.com). While training was completed in the eight locations, only five of the setting locations completed study interventions.

Reasons for lack of participation include difficulty in identification of appropriate patients, and lack of implementation of the intervention tools. One branch did not identify any patients as appropriate for the study even with regular dialogue and explanation. The other two locations submitted patients as participating in the study; however, review of the patient record by the project coordinator did not identify interventions to be considered as a study participant. Roadblocks will be additionally addressed in the study section.

Sample

The sample consisted of patients with an advancing disease state who were receiving skilled home health care. Criteria defined by Kelly et al. (2017) were used to enroll subjects: chronic advancing condition, decreased functional status or recent functional decline, and a hospitalization within the last 12 months. A home health episode is a period of 60 days. After the 60 day initial episode a patient can be recertified every 60 days. Thirty-five patients were enrolled in the study, 11 of whom were recertified, for a total of 46 home health episodes. Of the 46 episodes in this study, 18 were initial episodes, where the patient was enrolled in the study at admission to the home health agency.

Sample patient characteristics are presented in Table 1. The mean age of the participants was 77.1 (SD = 14.1) with a range of 41 to 102. Participants were predominately female (74.3%) and all but one participant were white (97.1%). An age distribution was completed consisting of four age groups of less than or equal to the traditional Medicare age (65), 66 to 77 years, 78 to 85, and over 85 years of age.

Table 1

Sample Patient Characteristics (N=35)

Characteristic	% (n)
Under 65	22.8% (8)
66-77	25.7% (9)
78-85	25.7% (9)
86+	25.7% (9)
Total	100.0% (46)
Sex	
Male	25.7% (9)
Female	74.3% (26)
Race	
White	97.1% (34)
Black	2.9% (1)

Diagnostic characteristics are shown in Table 2 for the 46 episodes completed. The primary diagnosis was identified from the specific episode plan of care. Diagnoses were categorized by system groupings using the International Statistical Classification of Diseases and

Related Health Problems ([ICD-10] World Health Organization, 1992). Respiratory and circulatory system groupings constituted the largest sets.

Table 2

Diagnosis by System Category using ICD-10 Code Groups (N=46)

System Category	% (n)
Respiratory	26.1% (12)
Circulatory	21.7% (10)
Neuro/Muscular	19.6% (9)
Digestive/Endocrine	13.0% (6)
Other	19.6% (9)

Note: N=46 represents episodes of care; 11 participants were recertified and completed more than one episode

Interventions

Training

Prior to implementation, training was provided to address needs identified in the gap analysis. Table 3 presents the identified gap and the training provided to address the need. A series of four training sessions were held over a period of 4-6 weeks at each location. Attendance included all staff for the initial project overview and CAPC Palliative overview which were provided by the project coordinator. The initial overview of the project included background and significance of the project, a review of the literature, palliative care principles, a theoretical framework, and the project design.

Next two specific courses selected from the CAPC training curriculum related to pain management were conducted in a group setting with all nursing staff in the location. This training session was conducted by the project coordinator or another hospice trained nurse manager. Another CAPC training curriculum relating to communication about prognosis was also conducted by the project coordinator with all nursing and MSW staff. Lastly, an in-service about communication skills that focused on goals of care, prognosis, and advanced care planning was conducted by a geriatric physician. Over 25 nurses and six MSWs completed the training.

Table 3

Gap and Training Plan

Gap	**Education**	**Audience**
Timing of Palliative Care	CAPC Training Curriculum: • In-depth Look at Palliative Care and Its Services • Overview of Project	All staff within the location
Comprehensive Care	CAPC Training Curriculum: • Pain Management Course 1&2 • Overview of Project	All nursing staff Optional for therapy staff
Communication Skills	CAPC Training Curriculum: • Discussing Prognosis In-service: • Communication Skills about Advanced Care Planning and Goals of Care	All nursing and MSW staff Optional for therapy staff
Continuity of Care Across the Settings	In-service: • Communication Skills about Advanced Care Planning and Goals of Care	All nursing and MSW staff Optional for therapy staff
Spiritual, Religious and Existential Aspects of Care	CAPC Training Curriculum: • Discussing Prognosis	All nursing and MSW staff Optional for therapy staff

Instruments

Symptom Management. The Edmonton System Assessment System ([ESAS], Appendix A) is a palliative care symptom assessment tool addressing 9 symptoms: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. The tool is a 10 point visual analogue scale on which patients circle the number that best represents the severity of their symptom, with 0 indicating lack of the symptom and 10 being the most severe experience of the symptom. It was developed for use in patients receiving palliative care and can provide a clinical profile of symptom severity over time (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). The tool has shown high test-retest reliability exceeding 0.8, and construct validity demonstrated by an overall Cronbach alpha of 0.79 – 0.93 (Richardson & Jones, 2009).

Quality of Life. The Palliative Outcome Scale ([POS], Appendix B) is a 10 item scale assessing physical, psychological, emotional, spiritual, and information and support needs (Hearn & Higginson, 1998). The tool demonstrates construct validity (Spearman rho = 0.43 – 0.80) with acceptable test/re-test reliability for seven of the items. Internal consistency is reported as a Cronbach's alpha of 0.65 for patients with advanced cancer (Hearn & Higginson, 1998). The tool has been used internationally for patients with advanced cancer and other advanced diseases (Van Vliet et al., 2015). The project coordinator registered the project on the website for permission to use in the study.

Spirituality. Although the POS has some items addressing spirituality, additional items were sought for a more comprehensive assessment. An abbreviated Comfort Questionnaire was created by selecting thirteen items (Appendix C) from the General Comfort Questionnaire, which is a 28 item tool designed to measure holistic comfort in hospitalized and community patients as defined by the middle range Comfort Theory (Kolcaba, 2003). The tool is part of the National Quality Measure Clearinghouse. Dr. Kolcaba gave permission for limited items on the tool to be used (K. Kolcaba, personal communication, March 2, 2017).

Palliative Performance Scale v2. Version 2 of the Palliative Performance Scale ([PPS v2], Anderson et al., 1996) is a publicly available tool routinely used in palliative and hospice care to communicate the current condition of the patient on a continuum of 10% increments from fully functioning (100%) to death (0%). The tool (Appendix D) consists of five observer-rated domains including ambulation, activity and evidence of disease, self- care, intake, and level of consciousness. Consistency and absolute agreement values were near 0.96, determining good reliability. Content validity was determined at the 30-40% levels (Ho et al., 2008).

Data Collection

The data collection plan is outlined in Table 4. The ESAS was to be completed on one nursing visit per week if a skilled visit was scheduled. Nursing visits were to include the Palliative Outcome Scale (POS) monthly throughout the 60 day episode planned in conjunction with a MSW visit each month. Changes in the plan of care were to be implemented using the POS clinical decision-making guide available through the POS website (http://pos-pal.org). During the project overview, the project coordinator reviewed the clinical decision making guide with all nursing and MSW staff and how the interventions were to be integrated into the skilled plan of care.

The Medical Social Worker (MSW) was to implement a family care conference monthly to communicate goals of care with the patient and family during traditional skilled visits related to community resources and other healthcare planning needs which usually include advanced directives. The MSW would also include discussions on advanced care planning and the completion of the Medical Order for Scope of Treatment (MOST) form (Appendix E) as appropriate (http://kbml.ky.gov/board/Documents/MOST%20Form.pdf). The MOST form is an advanced care planning document specific to Kentucky which is transferrable to any location. During monthly MSW skilled visits, the abbreviated Comfort Questionnaire was to be completed to assess spiritual comfort needs and intervene accordingly. The Palliative Performance Scale v2 was to be assessed at least monthly by the home health nurse or as needed with any changes in patient condition. The purpose was to guide subsequent goals of care discussions and appropriate hospice referral determinations.

Table 4

Data Collection and Intervention Plan with Responsible Persons

Week in Episode	**Advanced Disease Management Interventions**	**Responsible Person**
Week One	Edmonton System Assessment System	Nursing
	Complete Spiritual Assessment with Admission	Nursing
Week Two	Edmonton System Assessment System	Nursing
	Palliative Outcome Scale	Nursing
	Family Care Conference/Goals of Care	MSW & Nursing
	General Comfort Questionnaire	MSW
Week Three	Edmonton System Assessment System	Nursing
Week Four	Edmonton System Assessment System	Nursing
Week Five	Edmonton System Assessment System	Nursing
	Palliative Outcome Scale	Nursing
	Family Care Conference/Goals of Care/MOST form	MSW & Nursing
	General Comfort Questionnaire	MSW
Week Six	Edmonton System Assessment System	Nursing
Week Seven	Edmonton System Assessment System	Nursing
Week Eight	Edmonton System Assessment System	Nursing
Week Nine	Edmonton System Assessment System	Nursing
	Palliative Outcome Scale	Nursing
	Family Care Conference/Goals of Care	MSW& Nursing
	General Comfort Questionnaire	MSW

Therapy disciplines (physical therapy, occupational therapy, and speech therapy) continued to provide traditional skilled therapy. Traditional home health aide services were provided as ordered. These groups were included in the initial training and were expected to communicate with the primary nurse or nursing manager about changes in condition via regular team conferences or as needed.

Ethical Considerations

The project was approved by the Bellarmine University Institutional Review Board on June 24, 2017. Permission for this project was granted by Almost Family, Inc. All data files were stored on secured devices within the organization. Any paper copies were stored at the home office of Almost Family Inc.

Results

Patient Visits

Patients were entered into the study between June 24, 2017 and December 27, 2017. Data related to the episodes of care are displayed in Table 5. Cost data were retrieved from reports within the electronic medical record (EMR). The majority were reimbursed by Medicare and received an episodic payment. The remainder were paid at a per visit rate according to contract arrangements. Average reimbursement per episode was $2230.09 and average cost per episode was $1116.35. Of the 845 visits completed, 433 were nursing visits. Only 30 MSW visits were completed with the remainder being therapy and home health aide visits.

Table 5

Episode of Care Descriptive Statistics (N=46)

Episode Characteristic	% (n)
Episode Type	
Start of Care (SOC) episode	39.1% (18)
Recertification episode	60.9% (28)

Episode Characteristic	% (n)
Payer Type	
Episodic	82.6% (38)
Per Visit	17.4% (8)
Payer Source	
Medicare	82.6% (38)
Medicare Advantage	15.2% (7)
Private Insurance	2.2% (1)
Episodes by Location	
A	15.2% (7)
B	30.4% (14)
C	23.9% (11)
D	8.7% (4)
E	21.7% (10)
End of Episode Disposition	
Still Current at End of Episode	71.7% (33)
Discharged with Goal Met	8.7% (4)
Hospitalized at End of Episode*	8.7% (4)
Transferred to Hospice	2.2% (1)
Hospitalized and Expired	2.2% (1)
Discharged for Payer Authorization	2.2% (1)
Discharged for Non-Compliance	2.2% (1)

Visit Breakdown	M (SD)
Nursing	9.4 (2.5)
MSW	0.6 (0.9)
Therapy	5.2 (7.6)
Aide	3.0 (5.2)
TOTAL	18.0 (10.5)

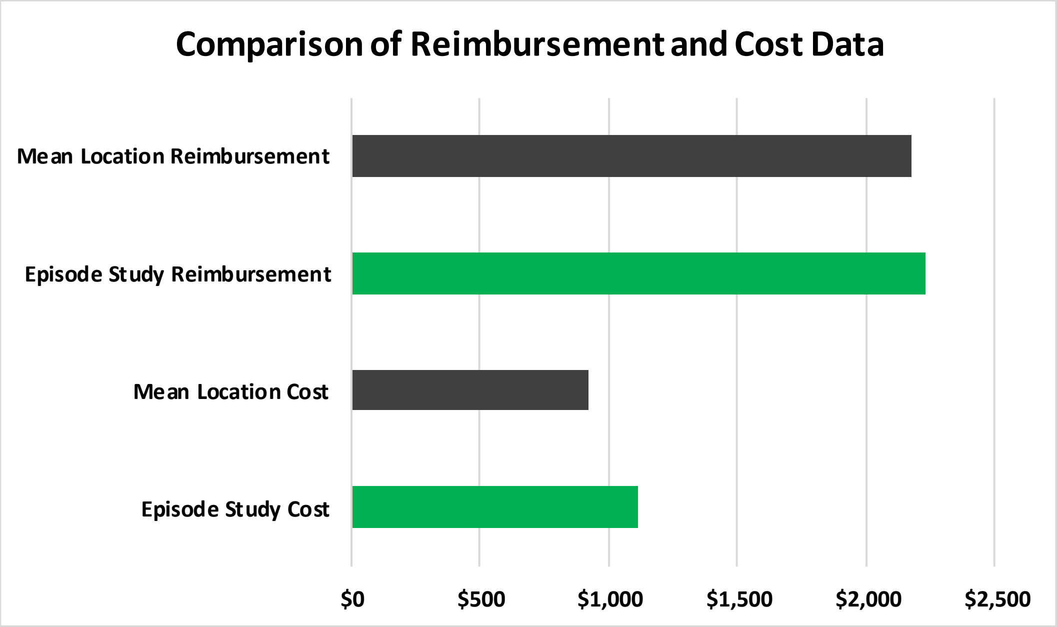
Episode Cost and Reimbursement	
Total Episode Cost	1116.35 (746.0)
Total Episode Reimbursement	2230.09 (1000.38)
Episode Margin	1113.73 (517.45)
Episode Margin Percentage	51.28 (26.23)

Note: Cost/Reimbursement and Margin results are in dollars
Note: Discipline Costs gathered from EMR data

Figure 4 displays the mean reimbursement and cost data for the study episodes compared to mean episodic reimbursement and costs in the organization for similar episodes. While reimbursement is slightly higher ($2180) than mean reimbursement of similar organization episodes ($2130), costs are also slightly higher ($1116 compared to $916). The margin is slightly lower (48.8%) in the study episodes to the mean margin for all similar episodes (57.0%) in the organization.

Figure 4

Cost and Reimbursement Comparison for Study Episodes and Location Means



Patient Assessments

Edmonton System Assessment System. Paired-samples *t*-test was conducted to determine any changes in the total ESAS score from the beginning of an episode to the end of the episode (See Table 6). There was a statistically significant increase in total ESAS scores (*t* (40) = -2.01, p < 0.04, 2 tailed), indicating increasing severity of symptoms.

Table 6

ESAS Scores Compared at the Beginning and the End of the Episode

	Beginning		Ending				95% CI	
	M	SD	M	SD	*t* (40)	*p*	LL	UL
Total ESAS	27.2	25.6	31.8	18.9	-2.08	0.04	-9.04	-0.1

CI - confidence interval; LL = lower limit; UL = upper limit.

Scores from patients who showed improvement in the ESAS were selected for paired-samples *t*-test to determine if the improvement was significant (see Table 7). The total ESAS score at the beginning of an episode was compared to the lowest score within the episode. There was a statistically significant decrease in total ESAS scores (*t* (30) = 6.07, p < 0.005, 2 tailed), indicating lessening of symptom severity.

Table 7

ESAS Scores Compared at the Beginning and the Lowest ESAS in the Episode

	Beginning		Lowest				95% CI	
	M	SD	M	SD	*t*(30)	*p*	LL	UL
Total ESAS	29.3	16.0	20.6	15.3	6.07	<.005	5.7	11.6

CI - confidence interval; LL = lower limit; UL = upper limit.

Palliative Outcome Scale. Data collection for the POS was limited to only 24 assessments. The study proposal planned for three assessments in each episode. Only 6 episodes had two POS assessments, preventing statistical analysis. The mean POS score was 18.7 (SD = 18.3). With ten items on the tool and a 0-4 scale, with higher scores indicating less quality of life and more need for intervention, the mean of 18.7 is just below the midline.

Abbreviated Comfort Questionnaire. Data collection for this measure was also limited, with only 10 of 46 possible assessments completed, preventing statistical analysis. The limited data collection for the POS and the abbreviated comfort questionnaire will be addressed in the discussion section.

MOST Form. A total of eighteen advanced care planning conversations took place during social worker visits. Nine MOST forms were completed as a result of these conversations for a 50% completion rate.

Hospitalization Outcomes

Since one of the goals of the project was to reduce hospitalizations, study hospitalization scores were compared to multi-state and national SHP scores. SHP is a healthcare data benchmarking company that provides metrics to post-acute providers.

Acute care hospitalizations. Hospitalization scores for the locations from July to December 2017 (the baseline period) were compared to the study group (see Table 8). Two types of scores are typically reviewed. Re-hospitalization is the return of a patient to the hospital within 30 days of an in-patient discharge, regardless of when the patient was admitted to the home health agency.

Acute care hospitalizations are hospitalizations after the admission to the home health agency. These scores (called acute care hospitalization scores) are reported in 30 day increments (31-60 days, 61-90 days, and 90+ days). In an effort to better compare the benchmark patient population with the study group, all orthopedic cases identified in SHP were eliminated from the N value. Hospitalizations occurred during 14 episodes of care. Each hospitalization was reviewed in relationship to the start of home healthcare to ensure appropriate placement in the data. None occurred during within the first 30 days post hospitalization. Eight of the 14 hospitalizations occurred more than 90 days from the most recent hospitalization.

Table 8

Comparison of Acute Care Hospitalizations in Study Episodes with Baseline Data

	Baseline	Non-Ortho Baseline	Multi State	National	Study Group Data
Total Cases	N=541	N=392	not available	not available	N=46
Range	% (n)	%(n)	%	%	%(n)
0-30 day	14.2% (84)	21.1% (83)	13.1%	12.2%	0.0% (0)
31- 60 day	3.3% (18)	4.6% (18)	5.0%	3.9%	6.5% (3)
61 - 90 day	1.3% (7)	1.7% (7)	1.6%	1.1%	6.5% (3)
91+ day	2.5% (12)	3.0% (12)	2.6%	1.8%	15.0% (8)
ALL	22.3% (121)	30.6% (120)	not available	not available	30.4% (14)

* All orthopedic cases are removed from total case number and associated hospitalization to better align baseline branch data with study sample population

Note: Baseline Data is July – December 2016; Study Period is July – Dec 2017

Thirty day re-hospitalization penalty diagnoses. There are few diagnoses for which hospitals are currently penalized financially if a patient returns to the hospital within thirty days of inpatient discharge. The 30 day rehospitalization rates for the penalty diagnoses were compared to baseline and benchmark data (see Table 9). There were 20 episodes eligible for a 30 day rehospitalization penalty. Only eight patients in these 20 episodes had a primary diagnosis in the penalty list. These diagnoses included 3 patients with Heart Failure, 5 with COPD, (noted as eligible cases in Table 9), and none with pneumonia. There were no hospitalizations within 30 days for any of the 8 cases.

Table 9

Thirty Day Rehospitalization Penalty Diagnosis Data

	Baseline Data				Study Data	
Diagnosis	Eligible Cases N=174	Actual % (n)	Multi-State	National	Eligible Cases N=8	Actual % (n)
Heart Failure	53	28.3% (15)	20.6%	20.1%	3	0% (0)
COPD	80	32.5% (26)	20.9%	18.7%	5	0% (0)
Pneumonia	47	25.5% (12)	19.4%	16.6%	0	0% (0)

Note: Baseline data is for July - Dec 2016 for the study locations

Organization Outcomes

Hospitalization scores of the baseline period and study period were compared for each of the five locations. First, the 30 day re-hospitalization scores during the study period for each of the five study locations were compared to the location specific baseline data (Table 10). A graph of this data is displayed in Figure 5. Each period has a relative multi-state and national benchmark score and are shown respectively on the figures.

Table 10

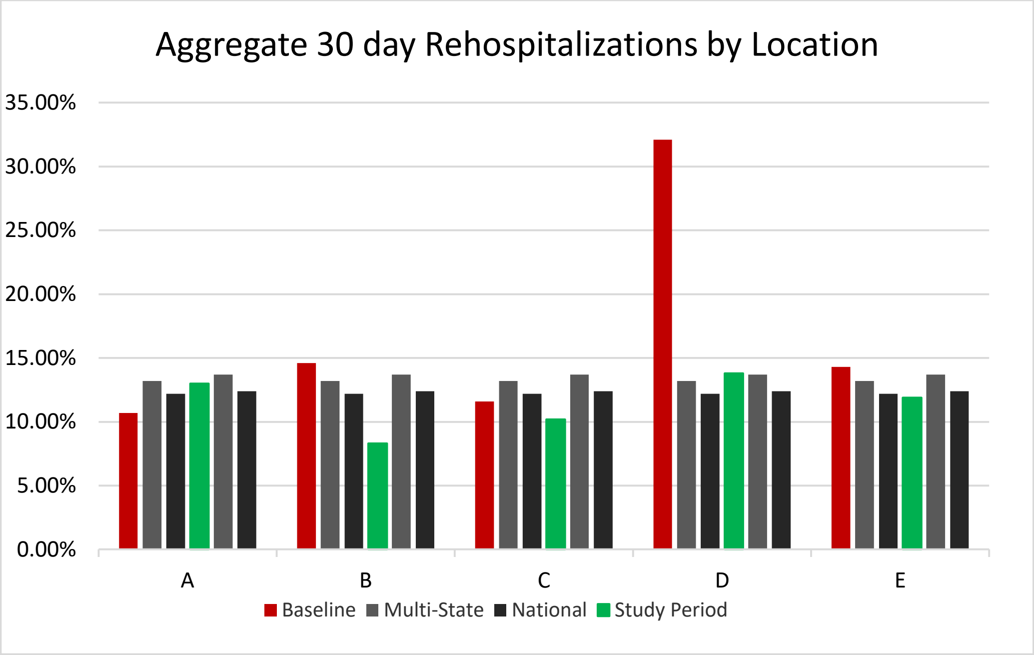
Aggregate 30 Day Re-hospitalizations by Location

Location	Baseline %	Study Period %
A	10.7%	13.0%
B	14.6%	8.3%
C	11.6%	10.2%
D	32.1%	13.8%
E	14.3%	11.9%
Multi State	13.2%	13.7%
National	12.2%	12.4%

NOTE: Baseline was July – Dec 2016; Study Period was July – Dec 2017

Figure 5

Aggregate 30 day Rehospitalizations by Location



Four of the five locations showed a decrease in 30 day re-hospitalization scores. The fifth location was already below the SHP baseline benchmark and increased only 2.3% to between the multi-state and national SHP study period benchmark scores. Of the four locations that showed decreases, all but one achieved scores below the SHP study period score. The location that did not achieve below the SHP study period benchmark had a decrease of over 15% and was within 0.1% of the multi-state SHP study period benchmark.

Next, acute care hospitalizations (patients admitted to an inpatient facility within 60 days of home health admission) were compared in Table 11, with Figure 6 displaying a graph of these changes and a comparison to the multi-state and national benchmarks for each distinct period. All five locations showed decreases (improvements) in acute care hospitalization scores with all location scores below the multi-state study period SHP benchmark and four of the five locations also achieving scores below the national study period benchmark.

Table 11

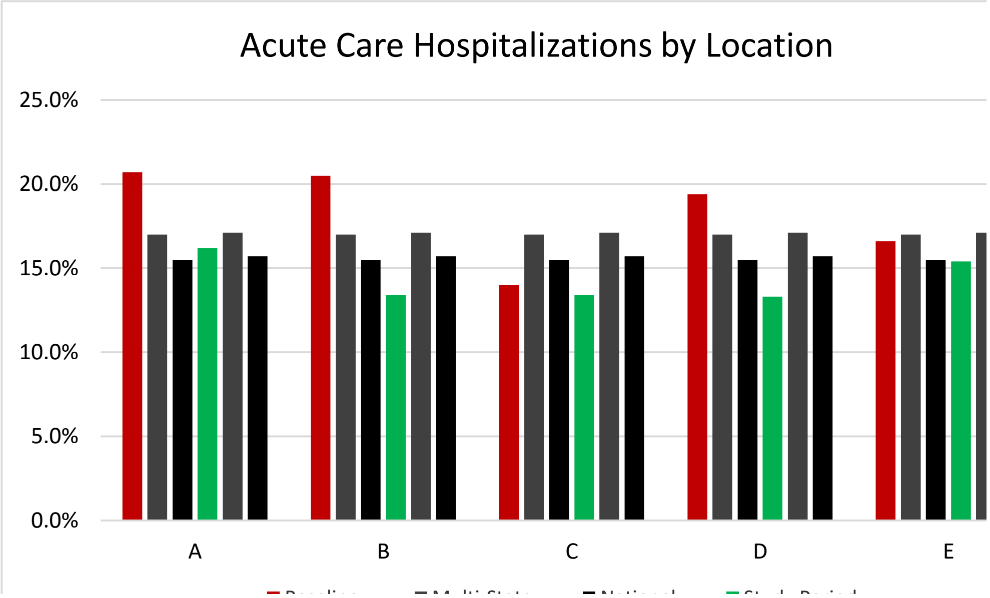
Acute Care Hospitalizations by Location

Location	Baseline %	Study Period %
A	20.7%	16.2%
B	20.5%	13.4%
C	14.0%	13.4%
D	19.4%	13.3%
E	16.6%	15.4%
Multi-State	17.0%	17.1%
National	15.5%	15.7%

NOTE: Baseline was July – Dec 2016; Study Period was July – Dec 2017

Figure 6

Aggregate Acute Care Hospitalizations by Location



Aggregate Pain Improvements Data

Improvement in pain is a specific outcome reported through SHP in the aggregate with a comparison to the SHP multi-state and national scores. All five study locations showed an increase in the Improvement in Pain score from baseline to study period, with changes ranging from 1.4% to 15.9%. In comparison, multi-state and national improvement scores changed 2.3% and 3.3% respectively. Scores in three of the study locations improved 10% or more, with one nearly achieving the national rate. Figure 7 represents a comparison of the changes in relation to SHP benchmark data.

Table 12

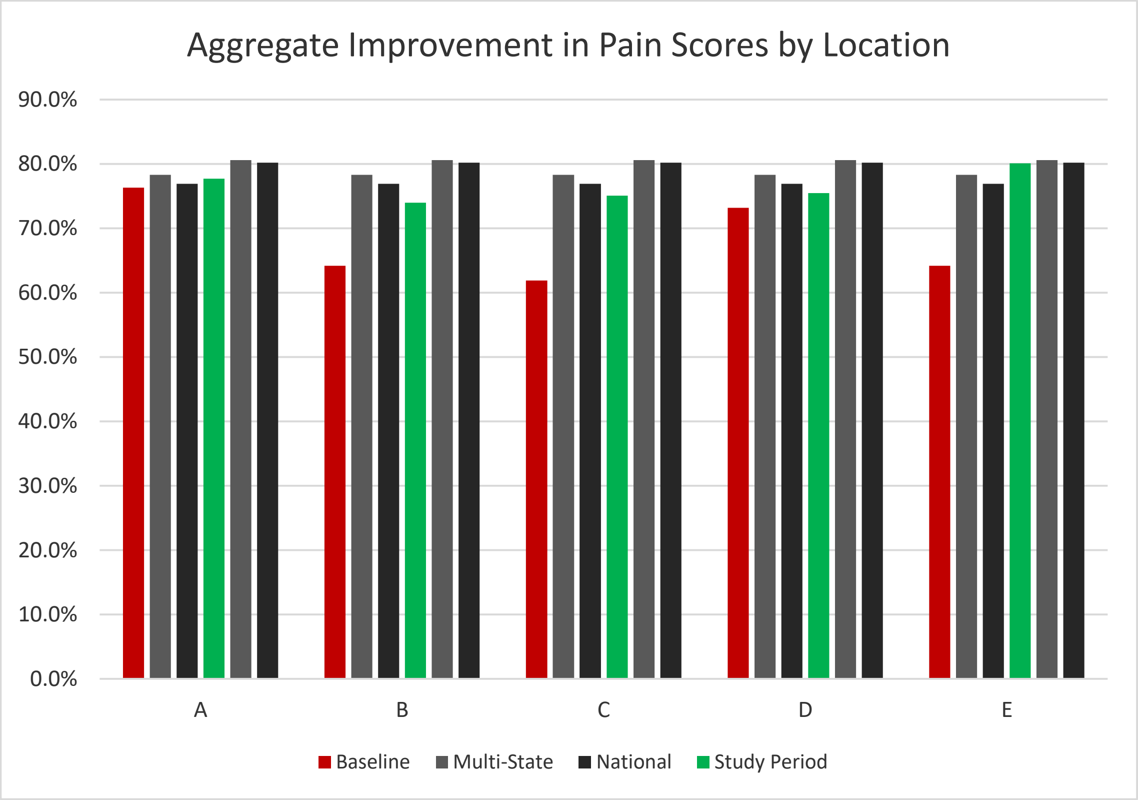
Improvement in Pain Scores by Location

Location	Baseline %	Study Period %
A	76.3%	77.7%
B	64.2%	74.0%
C	61.9%	75.1%
D	73.2%	75.5%
E	64.2%	80.1%
Multi-State	78.3%	80.6%
National	76.9%	80.2%

NOTE: Baseline was July – Dec 2016; Study Period was July – Dec 2017

Figure 7

Improvement in Pain Scores by Location



Discussion

Project Outcomes

The ESAS results from beginning to end of episode showed a statistically significant increase in symptom severity, although there were also significant periods of reduction in symptom severity during the episode. These findings indicate that improvements in palliative symptoms occurred and then either exacerbated, or new symptoms arose within the episode. The increasing symptom severity may be a result of the extended time period in this study (60 days) and reflect the typical disease progression of chronic illness over time. As palliative interventions are continually refined, data will be compared to determine improvements in symptom management. Unfortunately, other patient assessment data were not able to be analyzed due to low numbers of instrument collection.

Most of the patients were recertified at the end of the episode in the study (71.7%), showing a continued need for skilled care. The use of the ESAS proved to be a valuable tool to trend data and identify incremental changes in symptom severity. These small changes in patient condition might not otherwise have been identified, posing a risk that the patient would be discharged with unresolved symptoms.

While the MSW visits were much fewer than expected, and will be discussed later, the visits that did occur all resulted in an advanced care planning discussion and 50% resulted in the completion of the MOST form. During project implementation, conversations with healthcare stakeholders indicated the value of having the MOST form initiated during the home health episode and available in case of necessary visits to a hospital or other healthcare provider. The value of these conversations and resulting completed MOST forms has the potential to contribute to quality of life, honoring of patient wishes, and avoidance of unwanted and costly hospitalizations and treatments.

While 20 of the 46 episodes were entered into the study post-hospitalization, none returned to the hospital within 30 days. With an average daily cost of approximately $1600 for a hospitalization (https://www.beckershospitalreview.com), the savings of one three day hospital stay is $4800. Based on this eligible study patient population (20) and using the national benchmark rehospitalization rate of 13.7%, the study savings is $13,152.

While the overall hospitalization scores were similar (30. 6% baseline and 30.4% study period), the first 60 day scores are significantly lower (16.1% baseline and 6.5% study period). The 90 day and above score for the study period was, however, significantly higher than the benchmark (3.0% baseline and 15.0% study period). One explanation is the much larger percentage of recertification episodes in the study proportion. Based on organizational data, start of care (SOC) episodes account for 60% to 65% of all episodes. The study episode proportion was only 39.1%. Therefore, a much larger percentage of the study episodes were eligible for the 90 day and above hospitalization calculation.

In the aggregate comparisons, 4 of the 5 locations showed a decrease in the 30 day re-hospitalization score, ranging from +2.3% to -18.3%. The one location that did have an increase was already below the multi-state and national benchmarks and improved to a score between the multi-state and national scores. All five locations had a decrease in the 60 day acute care hospitalization scores with decreases of -0.1% to -7.1%.

Lastly, the improvement in pain SHP scores was an unexpected outcome, particularly in light of the increasing symptom severity scores reported in the ESAS. In addition to the training provided, staff asked for a pocket resource with the pain assessment and pain medication management information to reference for effective communication with other healthcare providers. This tool was created (Appendix F) and will be used in going forward.

Project Implementation Challenges and Limitations

Intervention scheduling. As with any new integration plan, there were several roadblocks and lessons learned both with the design and with the integration itself. First, the frequency of the planned skilled MSW visits was not feasible nor necessary. This led to a lack of data for two of the planned interventions. Since the abbreviated Comfort Questionnaire was to be completed on the MSW visit, and the POS was to be coordinated along with the MSW visit (by the nurse), the frequency of these tools was considerably less than planned. Additionally, lack of communication between the skilled disciplines during some patient episodes omitted the MSW from the plan of care in several instances. Additionally, some of the patients could not receive MSW visits due to lack of authorization from the payer. While only eight episodes were from Medicare Managed Care payers, these payers will not authorize the use of an MSW. Additional reasons for lack of MSW visits were scheduling difficulties with the patient and family, refusals, or lack of need for skilled care.

Electronic Medical Record integration. Another significant contributing factor was a planned electronic medical record (EMR) integration for the organization during the study period. The study period was from June 24, 2017 until December 31, 2017. The EMR rollout began in mid-June and was not completed for the study locations until December 2017. Learning the new system created challenges in every aspect of operations. This also led to a lack of coordination in adding the MSW to the plan of care and scheduling of visits.

Leadership opportunities. Finally, developing and implementing a new intervention strategy for a limited population of patients created its own challenges. Staff were trained in a total of eight locations during the study period over several months. This included nearly 20 clinical nursing management staff, more than 25 nurses, and 5 MSWs. The first challenge was creating understanding within the teams related to appropriate selection of patients for the interventions. Regular follow up with the branch directors was necessary. The new electronic medical record required learning to run reports to identify patients with appropriate diagnoses, a process which took several weeks to accomplish. Manual tracking of patients in the study had to occur until a solution was identified.

Several locations were not able to completely integrate the palliative care delivery. Of the eight branches, three had no patients in the study. Identified reasons included a lack of leadership engagement and a continued lack of understanding of appropriate patient selection. As the study ended, these roadblocks and learnings have created opportunities for improvement in further implementation and process measure improvement for study locations and new locations as they choose to implement this model of care.

Executive leaders have many intervening priorities for the patients, employees, and the organization they serve. Decisions must be made when to move forward and when to halt different initiatives with competing time frames. In this instance, since the study intervention model had not been tested, allowing three of the eight branches not to participate was necessary due to other management and staff priorities.

One additional learning was related to formal and informal leaders. The initial branch that implemented the intervention had a nurse manager who was actively engaged in the process and became a trainer to other branches and a leader to drive implementation and compliance. As other branches received training, those that did not naturally develop a champion, either in the management staff or within the nursing or MSW staff, found themselves not implementing the intervention model. As a nurse leader, looking for an active champion can be key to success, especially if initial buy-in does not happen at the director level of the location.

Study Limitations

Several limitations were identified. First, only 35 individual patients were included in the study. While there were 46 total episodes, a larger number were subsequent episodes as opposed to patients newly admitted to home health services which is not typical of a home health census. Cultural diversity is another identified issue. While there were five locations involved, only one patient was non-white. Also, while study locations were both metropolitan and rural areas, all were within one state.

Adjustments to the Intervention Schedule

It was identified that the abbreviated Comfort Questionnaire and the POS had areas of overlap and having both was complicated to coordinate. It was decided that one MSW visit for assessing both spirituality and quality of life was a viable solution. Since the POS had both quality of life and spirituality components, it was chosen as the single intervention tool. It was also decided that one MSW visit for a 60 day certification period seemed appropriate to meet these needs. The study demonstrated that the initial MSW visit generally created a beginning discussion about advanced care planning needs and many times resulted in initiation of the MOST form. Other visits could be planned as a need for skilled care is identified.

The second issue was the ability to offer quality of life and spirituality assessments when an MSW is not authorized by a payer or the patient refuses an MSW visit. The option of a telephonic visit was determined to be an appropriate solution. The MSW will be added to the EMR team assigned to the patient even if an order for a visit is not obtained and a phone call will be made during the episode to complete the POS for quality of life and spirituality needs assessment. Then intervention strategies can be coordinated with the rest of the home health team with the MSW from the office.

Electronic Medical Record System Improvements

As the organization implemented the new EMR, opportunities arose to use the system to identify appropriate patients at admission, ease scheduling of interventions, and identify patients receiving the palliative interventions. A special care type code was created allowing reports to be run to track study patients and on-going patients post study. Second, because the actual intervention tools were still on paper, a buddy code was created in the EMR scheduling console to remind the nursing and MSW staff when to complete the intervention. Lastly, an attachment code was created for each separate tool so that the paper copies could be uploaded into the EMR patient file. This made retrieval of study data much more efficient.

Integration of Palliative Care beyond the Study

The training portion of the study occurred in each branch, but no additional staff were formally trained as they were brought into the organization. A training plan needed to be packaged for the current eight locations and then for new locations as they were added. A train the trainer process has been developed and is being used to implement the adjusted training and intervention model into other locations in Kentucky and into Indiana.

The training schedule was also adjusted as the new Conditions of Participation came into effect in January 2018 adding ‘goals of care’ as a distinct requirement of the patient plan of care. Since training on goals of care has now become integrated into the orientation process, a goals of care discussion is not necessary. Therefore, the final in-service regarding communication about prognosis and advanced care planning that was originally delivered by a geriatric physician, has been revised. Now the MSW at the location provides an in-service around communication about advanced care planning, and the process of completing the state advanced care planning form, the MOST. As staff in other states are trained, the state appropriate advanced care planning form must also be identified and added to the training material.

Assessment of Project Success

The purpose of this project was to integrate evidence-based palliative interventions into home care for patients with advanced disease, with the goal of improving patient outcomes and reducing hospitalizations. The advanced diseases noted in the study population were primarily respiratory and cardiac, consistent with organization and national data.

The interventions were completed with a varying degree of consistency due to multiple factors. The implementation of the ESAS on a regular basis showed the most compliance and was important in identifying incremental changes in the advanced disease state through fluctuations in symptom severity scores. Although improvement in palliative symptoms was not achieved from baseline to end of episode, the ESAS was instrumental in documenting ongoing symptom management needs and potential skilled care needs. ESAS scores will continue to be examined as changes are made in palliative care interventions, study protocols, full implementation of the EMR and prompt identification of patients, and training of all staff.

Communication with patients and families about prognosis was an important outcome resulting from the MSW advanced care planning conversations. The number of MOST forms completed demonstrates the ability of an interdisciplinary care team to provide necessary communication around prognosis and end of life planning. Nine patients in this study had the opportunity to engage in choices about their end of life care.

Lastly, decreases in the number of patients requiring hospitalization was a key outcome for the study. The study showed a 0% rate for the twenty patient who were eligible for a 30 day rehospitalization compared to the benchmark rate of 13.7%. That was a calculated savings of over $13,000. Replication of those results for 1000 patients would result in a total cost savings of over $500,000.

Overall, the project provided meaningful data on the effects of evidenced-based palliative care integration into home healthcare for patients with advancing disease states. Ongoing improvements in interventions and processes will allow for further examination of patient and organization outcomes. This project provides a first step in addressing the changes needed in home health care as the number of individuals living at home with chronic diseases continues to increase.

Conclusion

Research has demonstrated that palliative care can have positive effects on patient outcomes and improve other healthcare outcomes in the home health setting. The body of literature needs to be expanded to continue defining and supporting these findings. As our population ages, the healthcare system will need this evidence to build and support practice guidelines for those patients with serious illness and advanced disease. Home health organizations have an opportunity to provide positive clinical outcomes through evidence-based palliative practice while optimizing health care resources. This project has provided further evidence to guide home health leaders in the care of those with advancing disease.

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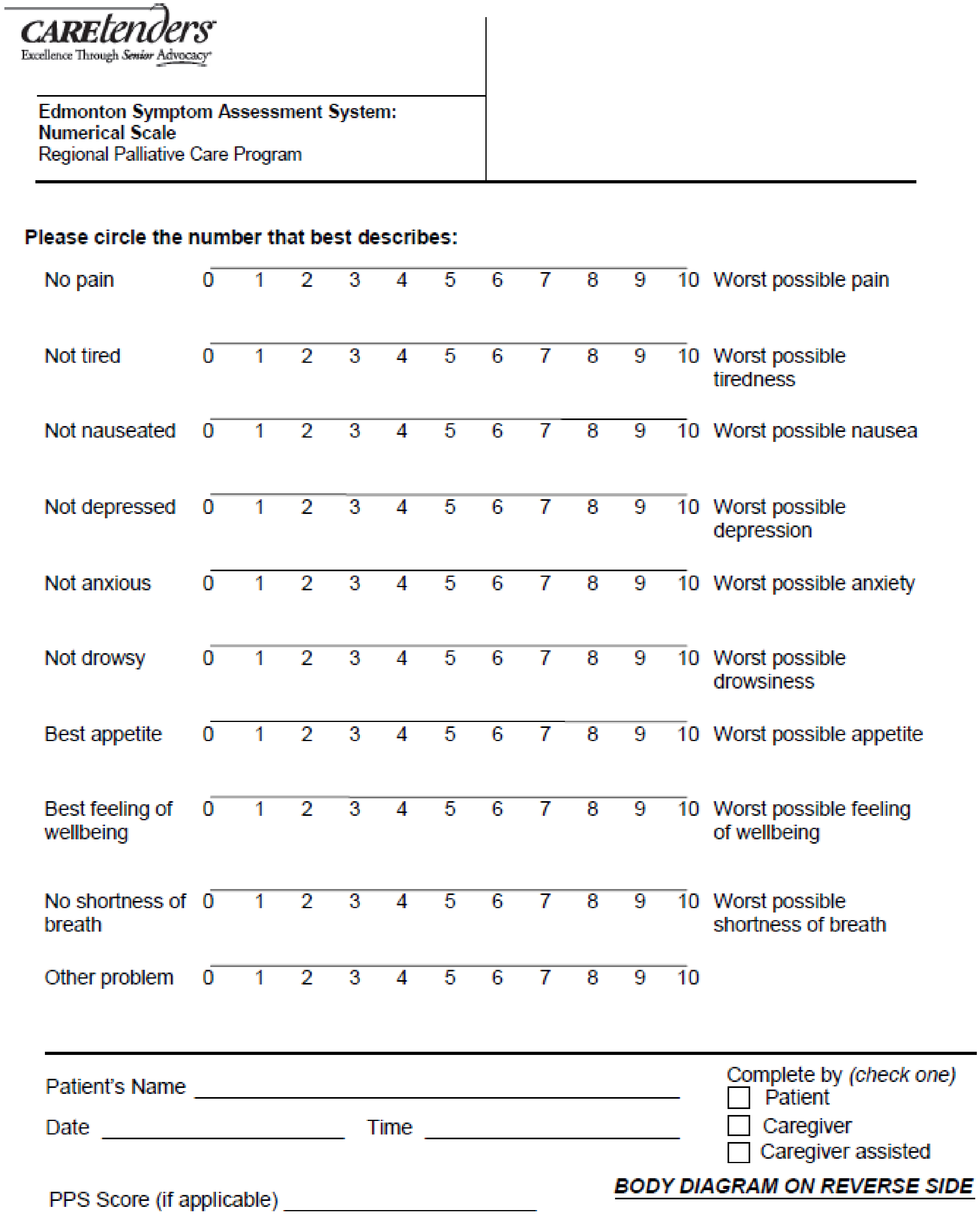
Appendix A

Edmonton Symptom Assessment System



CAREtenders
Excellence Through Senior Advocacy

Edmonton Symptom Assessment System:
Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name ______________________________

Date ______________ Time ______________

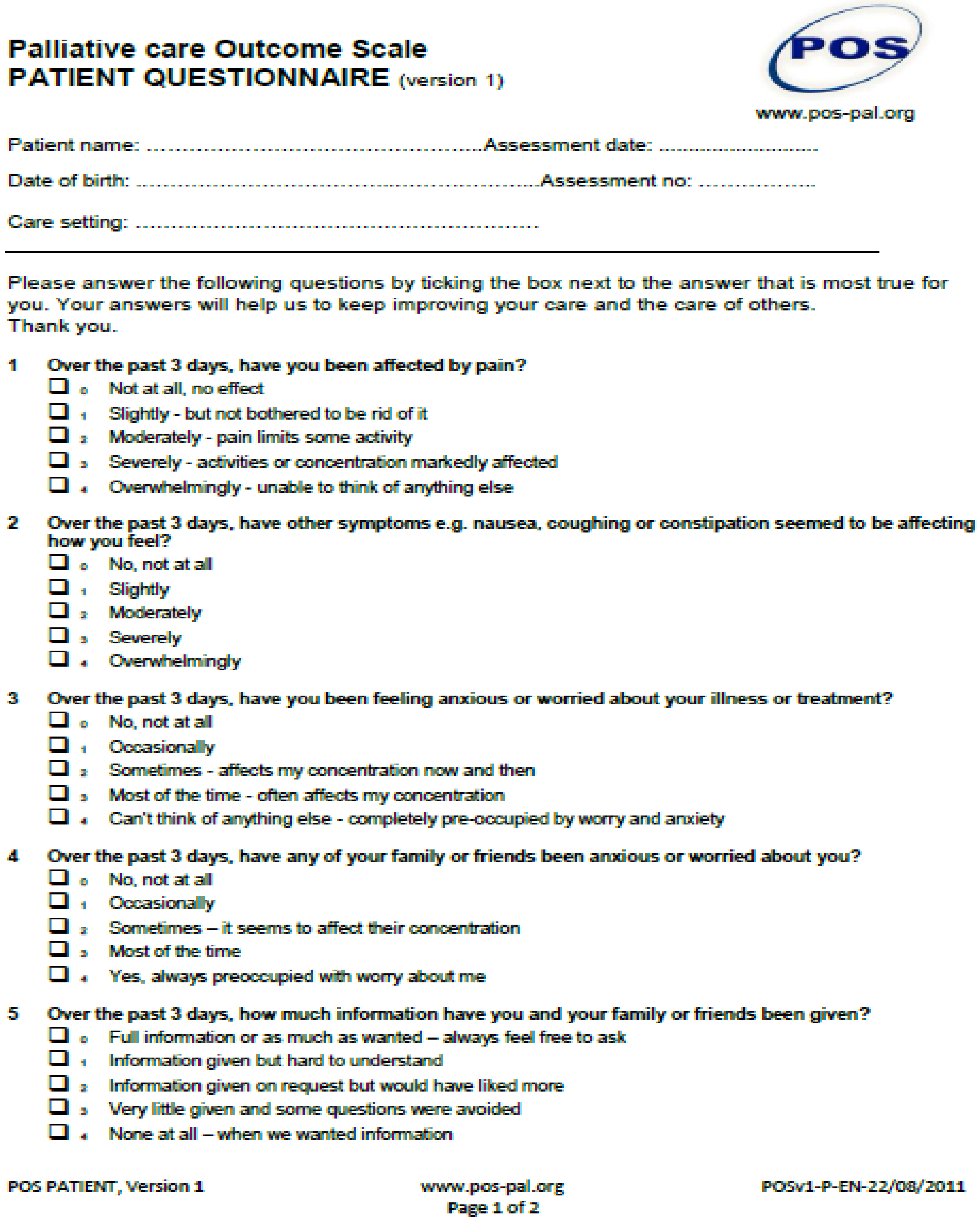
Complete by *(check one)*
☐ Patient
☐ Caregiver
☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

PPS Score (if applicable) ______________

Appendix B

Palliative Care Outcome Scale



Palliative care Outcome Scale
PATIENT QUESTIONNAIRE (version 1)

POS
www.pos-pal.org

Patient name: ………………………………………………Assessment date: ………………………
Date of birth: ……………………………………………………………Assessment no: ………………
Care setting: ……………………………………………………………

Please answer the following questions by ticking the box next to the answer that is most true for you. Your answers will help us to keep improving your care and the care of others.
Thank you.

1 Over the past 3 days, have you been affected by pain?
- ☐ 0 Not at all, no effect
- ☐ 1 Slightly - but not bothered to be rid of it
- ☐ 2 Moderately - pain limits some activity
- ☐ 3 Severely - activities or concentration markedly affected
- ☐ 4 Overwhelmingly - unable to think of anything else

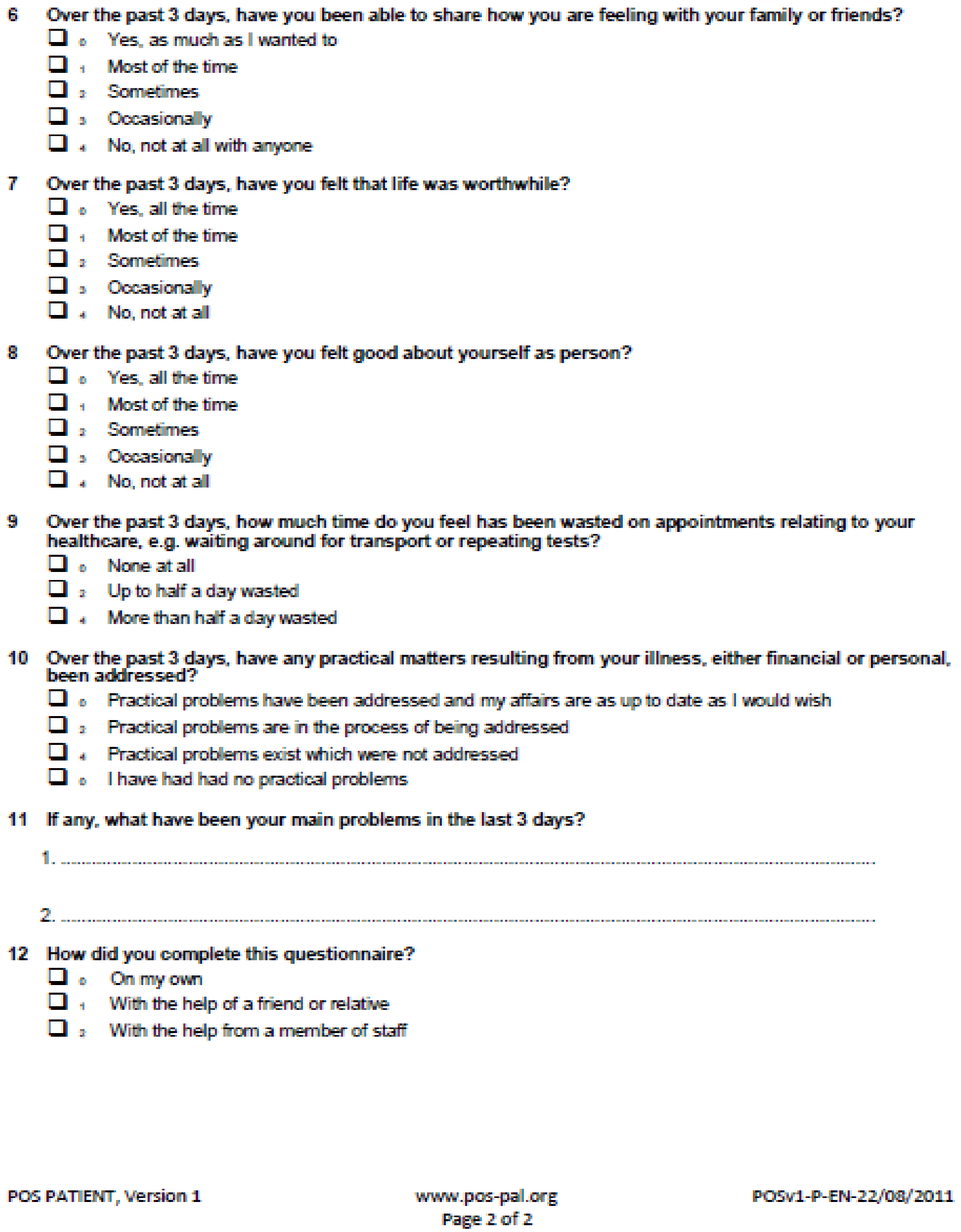
2 Over the past 3 days, have other symptoms e.g. nausea, coughing or constipation seemed to be affecting how you feel?
- ☐ 0 No, not at all
- ☐ 1 Slightly
- ☐ 2 Moderately
- ☐ 3 Severely
- ☐ 4 Overwhelmingly

3 Over the past 3 days, have you been feeling anxious or worried about your illness or treatment?
- ☐ 0 No, not at all
- ☐ 1 Occasionally
- ☐ 2 Sometimes - affects my concentration now and then
- ☐ 3 Most of the time - often affects my concentration
- ☐ 4 Can't think of anything else - completely pre-occupied by worry and anxiety

4 Over the past 3 days, have any of your family or friends been anxious or worried about you?
- ☐ 0 No, not at all
- ☐ 1 Occasionally
- ☐ 2 Sometimes – it seems to affect their concentration
- ☐ 3 Most of the time
- ☐ 4 Yes, always preoccupied with worry about me

5 Over the past 3 days, how much information have you and your family or friends been given?
- ☐ 0 Full information or as much as wanted – always feel free to ask
- ☐ 1 Information given but hard to understand
- ☐ 2 Information given on request but would have liked more
- ☐ 3 Very little given and some questions were avoided
- ☐ 4 None at all – when we wanted information

POS PATIENT, Version 1 **www.pos-pal.org** **POSv1-P-EN-22/08/2011**
Page 1 of 2



6 Over the past 3 days, have you been able to share how you are feeling with your family or friends?
- ☐ 0 Yes, as much as I wanted to
- ☐ 1 Most of the time
- ☐ 2 Sometimes
- ☐ 3 Occasionally
- ☐ 4 No, not at all with anyone

7 Over the past 3 days, have you felt that life was worthwhile?
- ☐ 0 Yes, all the time
- ☐ 1 Most of the time
- ☐ 2 Sometimes
- ☐ 3 Occasionally
- ☐ 4 No, not at all

8 Over the past 3 days, have you felt good about yourself as person?
- ☐ 0 Yes, all the time
- ☐ 1 Most of the time
- ☐ 2 Sometimes
- ☐ 3 Occasionally
- ☐ 4 No, not at all

9 Over the past 3 days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests?
- ☐ 0 None at all
- ☐ 2 Up to half a day wasted
- ☐ 4 More than half a day wasted

10 Over the past 3 days, have any practical matters resulting from your illness, either financial or personal, been addressed?
- ☐ 0 Practical problems have been addressed and my affairs are as up to date as I would wish
- ☐ 2 Practical problems are in the process of being addressed
- ☐ 4 Practical problems exist which were not addressed
- ☐ 0 I have had had no practical problems

11 If any, what have been your main problems in the last 3 days?

1. ………

2. ………

12 How did you complete this questionnaire?
- ☐ 0 On my own
- ☐ 1 With the help of a friend or relative
- ☐ 2 With the help from a member of staff

POS PATIENT, Version 1 www.pos-pal.org POSv1-P-EN-22/08/2011
Page 2 of 2

Appendix C

Abbreviated Comfort Questionnaire

Patient ID #________________

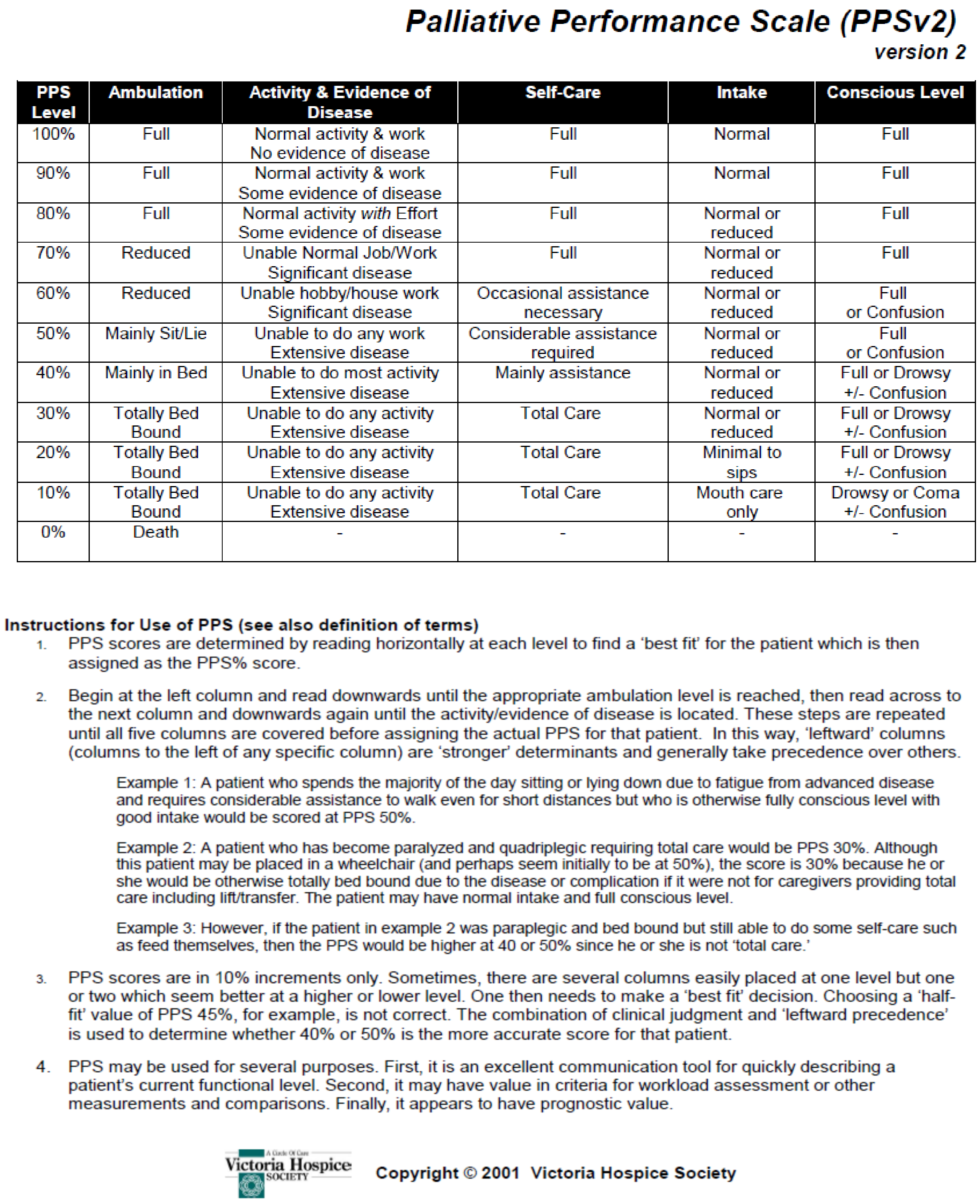
Below are statements that may describe your comfort right now. Six numbers are provided for each question; please circle the number you think most closely matches your feeling. This is about your comfort at the moment you are answering the questions.

	Strongly Disagree					Strongly Agree
I am glad I can fill out this questionnaire about my comfort	1	2	3	4	5	6
My body is relaxed right now	1	2	3	4	5	6
There are those I can depend on when I need help	1	2	3	4	5	6
I feel my life is worthwhile right now	1	2	3	4	5	6
I am inspired by knowing that I am loved	1	2	3	4	5	6
My faith helps me not be afraid	1	2	3	4	5	6
I am afraid of what is next	1	2	3	4	5	6
I have a favorite person(s) who makes me feel cared for	1	2	3	4	5	6
I have experience changes which make me feel uneasey	1	2	3	4	5	6
I would like to see my doctor/provider more often	1	2	3	4	5	6
My beliefs give me peace of mind	1	2	3	4	5	6
I feel out of control	1	2	3	4	5	6
I feel peaceful	1	2	3	4	5	6
I have found meaning in my life	1	2	3	4	5	6

http://www.thecomfortline.com

Appendix D

Palliative Performance Scale (version 2)



Palliative Performance Scale (PPSv2)

version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.

2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

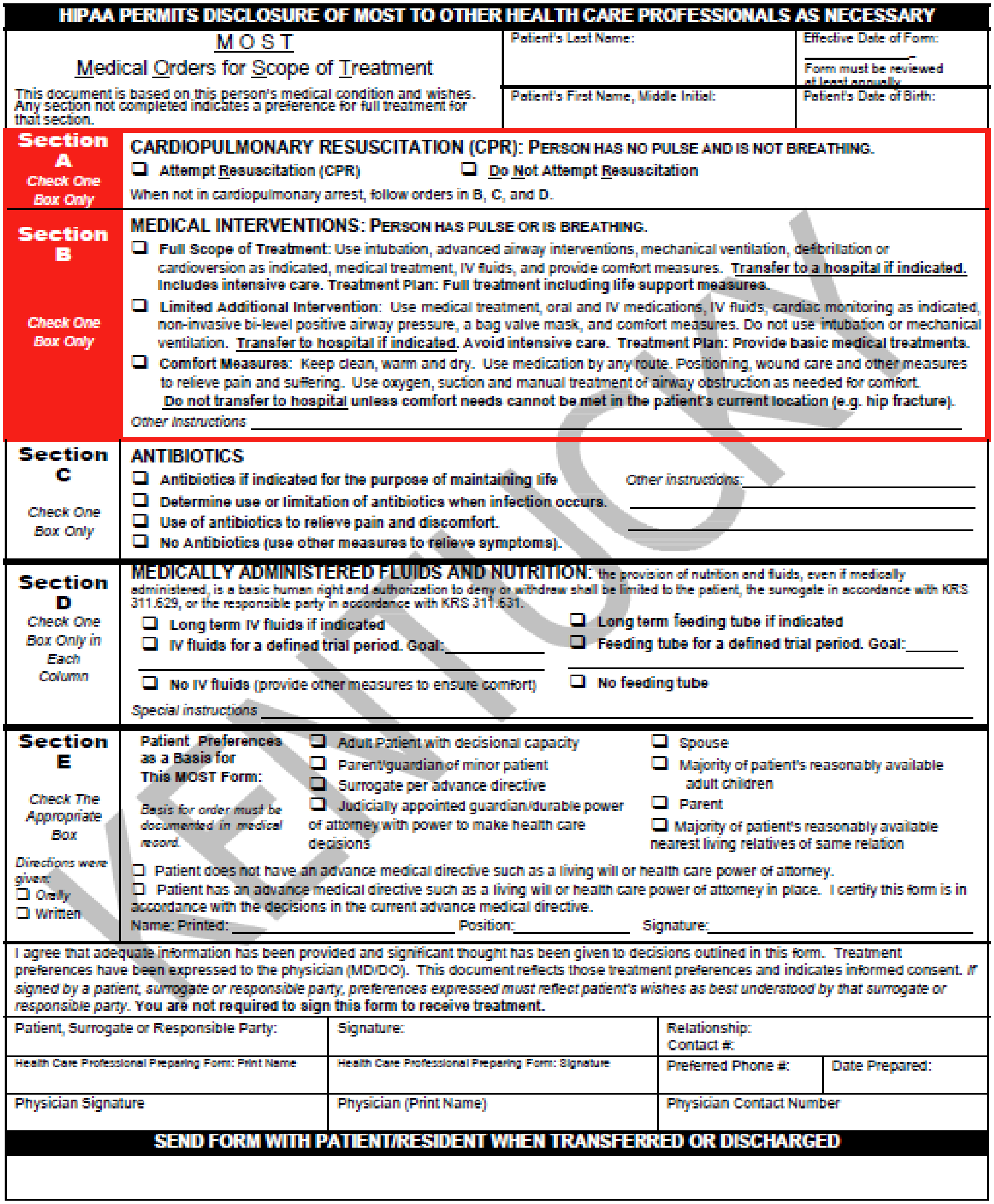
   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Appendix E

Medical Orders for Scope of Treatment (MOST)



HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

MOST

Medical Orders for Scope of Treatment

This document is based on this person's medical condition and wishes. Any section not completed indicates a preference for full treatment for that section.

Patient's Last Name:

Effective Date of Form: ______

Form must be reviewed at least annually.

Patient's First Name, Middle Initial:

Patient's Date of Birth:

Section A *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): PERSON HAS NO PULSE AND IS NOT BREATHING.

☐ Attempt Resuscitation (CPR) ☐ Do Not Attempt Resuscitation

When not in cardiopulmonary arrest, follow orders in B, C, and D.

Section B *Check One Box Only*

MEDICAL INTERVENTIONS: PERSON HAS PULSE OR IS BREATHING.

☐ **Full Scope of Treatment:** Use intubation, advanced airway interventions, mechanical ventilation, defibrillation or cardioversion as indicated, medical treatment, IV fluids, and provide comfort measures. **Transfer to a hospital if indicated. Includes intensive care. Treatment Plan: Full treatment including life support measures.**

☐ **Limited Additional Intervention:** Use medical treatment, oral and IV medications, IV fluids, cardiac monitoring as indicated, non-invasive bi-level positive airway pressure, a bag valve mask, and comfort measures. Do not use intubation or mechanical ventilation. **Transfer to hospital if indicated. Avoid intensive care. Treatment Plan: Provide basic medical treatments.**

☐ **Comfort Measures:** Keep clean, warm and dry. Use medication by any route. Positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in the patient's current location (e.g. hip fracture).**

Other Instructions ______

Section C *Check One Box Only*

ANTIBIOTICS

☐ **Antibiotics if indicated for the purpose of maintaining life**

☐ **Determine use or limitation of antibiotics when infection occurs.**

☐ **Use of antibiotics to relieve pain and discomfort.**

☐ **No Antibiotics (use other measures to relieve symptoms).**

Other instructions: ______

Section D *Check One Box Only in Each Column*

MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: the provision of nutrition and fluids, even if medically administered, is a basic human right and authorization to deny or withdraw shall be limited to the patient, the surrogate in accordance with KRS 311.629, or the responsible party in accordance with KRS 311.631.

☐ **Long term IV fluids if indicated**

☐ **IV fluids for a defined trial period. Goal:** ______

☐ **No IV fluids** (provide other measures to ensure comfort)

☐ **Long term feeding tube if indicated**

☐ **Feeding tube for a defined trial period. Goal:** ______

☐ **No feeding tube**

Special instructions ______

Section E *Check The Appropriate Box*

Directions were given:

☐ *Orally*

☐ Written

Patient Preferences as a Basis for This MOST Form:

Basis for order must be documented in medical record.

☐ Adult Patient with decisional capacity

☐ Parent/guardian of minor patient

☐ Surrogate per advance directive

☐ Judicially appointed guardian/durable power of attorney with power to make health care decisions

☐ Spouse

☐ Majority of patient's reasonably available adult children

☐ Parent

☐ Majority of patient's reasonably available nearest living relatives of same relation

☐ Patient does not have an advance medical directive such as a living will or health care power of attorney.

☐ Patient has an advance medical directive such as a living will or health care power of attorney in place. I certify this form is in accordance with the decisions in the current advance medical directive.

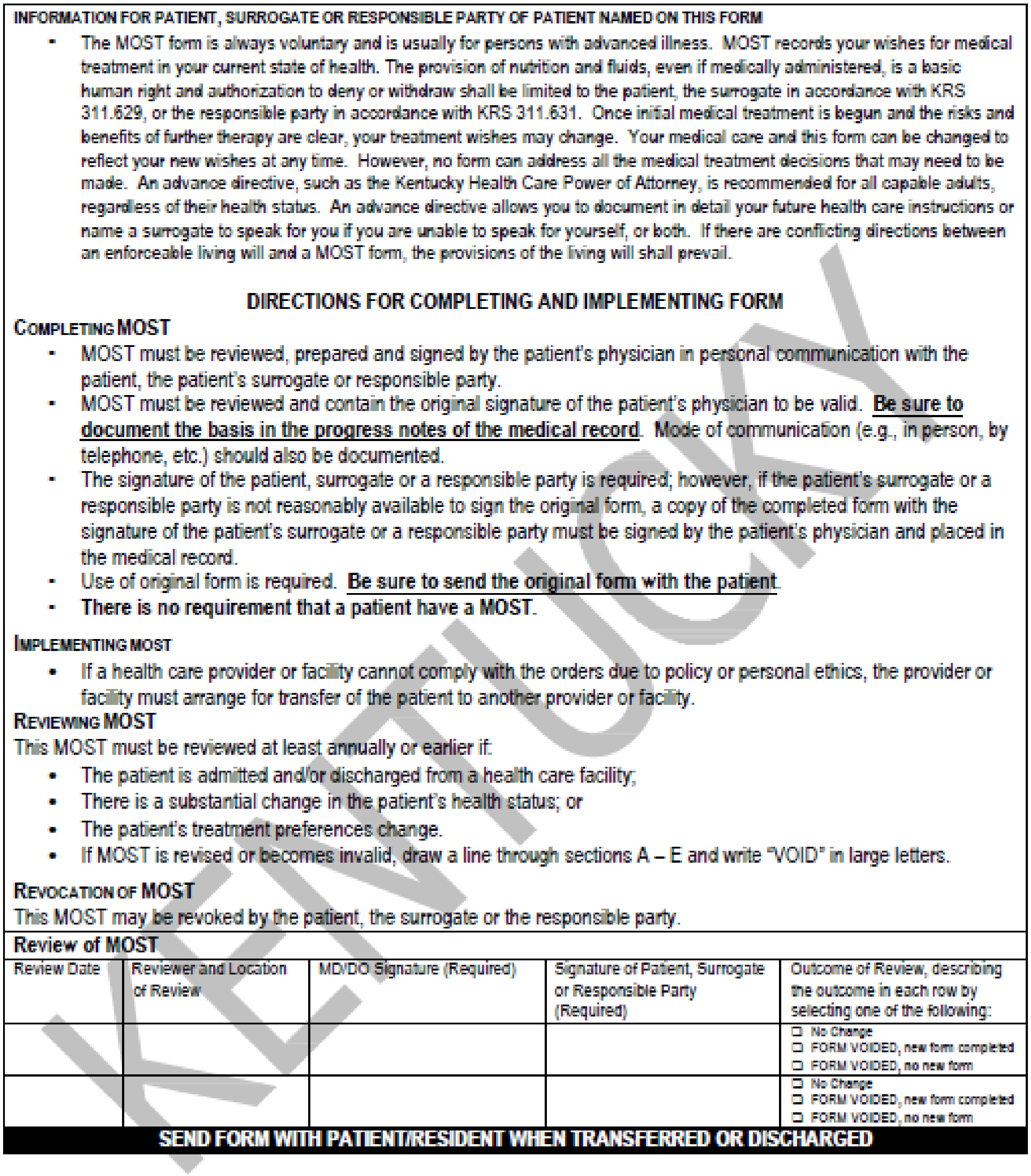
Name: Printed: ______ Position: ______ Signature: ______

I agree that adequate information has been provided and significant thought has been given to decisions outlined in this form. Treatment preferences have been expressed to the physician (MD/DO). This document reflects those treatment preferences and indicates informed consent. *If signed by a patient, surrogate or responsible party, preferences expressed must reflect patient's wishes as best understood by that surrogate or responsible party.* **You are not required to sign this form to receive treatment.**

Patient, Surrogate or Responsible Party:	Signature:	Relationship: Contact #:	
Health Care Professional Preparing Form: Print Name	Health Care Professional Preparing Form: Signature	Preferred Phone #:	Date Prepared:
Physician Signature	Physician (Print Name)	Physician Contact Number	

SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

(front page)



INFORMATION FOR PATIENT, SURROGATE OR RESPONSIBLE PARTY OF PATIENT NAMED ON THIS FORM

- The MOST form is always voluntary and is usually for persons with advanced illness. MOST records your wishes for medical treatment in your current state of health. The provision of nutrition and fluids, even if medically administered, is a basic human right and authorization to deny or withdraw shall be limited to the patient, the surrogate in accordance with KRS 311.629, or the responsible party in accordance with KRS 311.631. Once initial medical treatment is begun and the risks and benefits of further therapy are clear, your treatment wishes may change. Your medical care and this form can be changed to reflect your new wishes at any time. However, no form can address all the medical treatment decisions that may need to be made. An advance directive, such as the Kentucky Health Care Power of Attorney, is recommended for all capable adults, regardless of their health status. An advance directive allows you to document in detail your future health care instructions or name a surrogate to speak for you if you are unable to speak for yourself, or both. If there are conflicting directions between an enforceable living will and a MOST form, the provisions of the living will shall prevail.

DIRECTIONS FOR COMPLETING AND IMPLEMENTING FORM

COMPLETING MOST

- MOST must be reviewed, prepared and signed by the patient's physician in personal communication with the patient, the patient's surrogate or responsible party.
- MOST must be reviewed and contain the original signature of the patient's physician to be valid. **Be sure to document the basis in the progress notes of the medical record**. Mode of communication (e.g., in person, by telephone, etc.) should also be documented.
- The signature of the patient, surrogate or a responsible party is required; however, if the patient's surrogate or a responsible party is not reasonably available to sign the original form, a copy of the completed form with the signature of the patient's surrogate or a responsible party must be signed by the patient's physician and placed in the medical record.
- Use of original form is required. **Be sure to send the original form with the patient**.
- **There is no requirement that a patient have a MOST.**

IMPLEMENTING MOST

- If a health care provider or facility cannot comply with the orders due to policy or personal ethics, the provider or facility must arrange for transfer of the patient to another provider or facility.

REVIEWING MOST

This MOST must be reviewed at least annually or earlier if:

- The patient is admitted and/or discharged from a health care facility;
- There is a substantial change in the patient's health status; or
- The patient's treatment preferences change.
- If MOST is revised or becomes invalid, draw a line through sections A – E and write "VOID" in large letters.

REVOCATION OF MOST

This MOST may be revoked by the patient, the surrogate or the responsible party.

Review of MOST

Review Date	Reviewer and Location of Review	MD/DO Signature (Required)	Signature of Patient, Surrogate or Responsible Party (Required)	Outcome of Review, describing the outcome in each row by selecting one of the following:
				☐ No Change ☐ FORM VOIDED, new form completed ☐ FORM VOIDED, no new form
				☐ No Change ☐ FORM VOIDED, new form completed ☐ FORM VOIDED, no new form

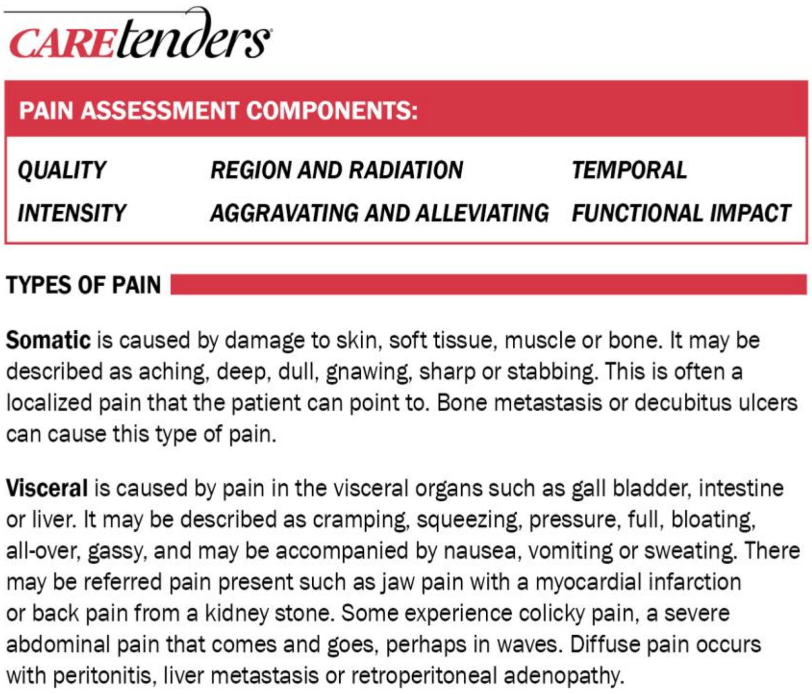
SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

(back page)

kbml.ky.gov/board/Documents/**MOST Form**.pdf

Appendix F

Pain Assessment and Symptom Management Cards



CARE*tenders*

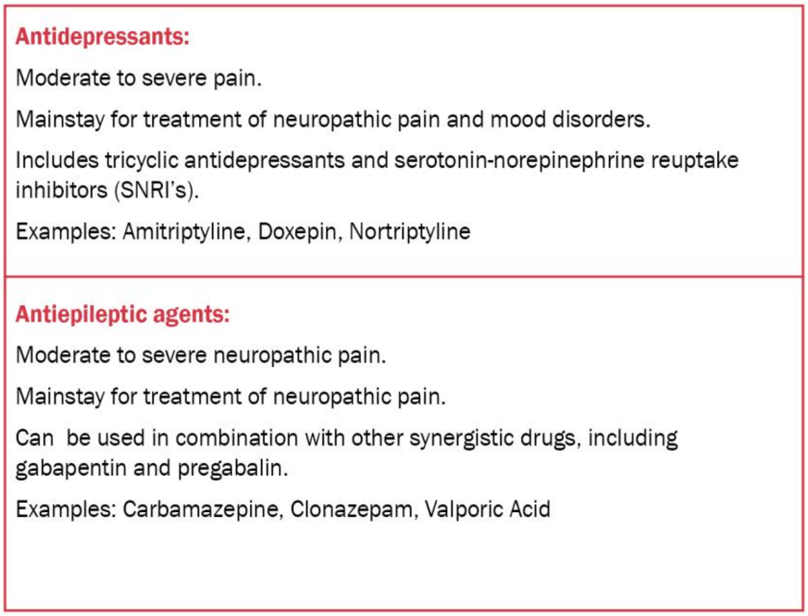
PAIN ASSESSMENT COMPONENTS:

QUALITY	***REGION AND RADIATION***	***TEMPORAL***
INTENSITY	***AGGRAVATING AND ALLEVIATING***	***FUNCTIONAL IMPACT***

TYPES OF PAIN

Somatic is caused by damage to skin, soft tissue, muscle or bone. It may be described as aching, deep, dull, gnawing, sharp or stabbing. This is often a localized pain that the patient can point to. Bone metastasis or decubitus ulcers can cause this type of pain.

Visceral is caused by pain in the visceral organs such as gall bladder, intestine or liver. It may be described as cramping, squeezing, pressure, full, bloating, all-over, gassy, and may be accompanied by nausea, vomiting or sweating. There may be referred pain present such as jaw pain with a myocardial infarction or back pain from a kidney stone. Some experience colicky pain, a severe abdominal pain that comes and goes, perhaps in waves. Diffuse pain occurs with peritonitis, liver metastasis or retroperitoneal adenopathy.



Antidepressants:

Moderate to severe pain.

Mainstay for treatment of neuropathic pain and mood disorders.

Includes tricyclic antidepressants and serotonin-norepinephrine reuptake inhibitors (SNRI's).

Examples: Amitriptyline, Doxepin, Nortriptyline

Antiepileptic agents:

Moderate to severe neuropathic pain.

Mainstay for treatment of neuropathic pain.

Can be used in combination with other synergistic drugs, including gabapentin and pregabalin.

Examples: Carbamazepine, Clonazepam, Valporic Acid

TYPES OF PAIN (cont.)

Neuropathic Pain is caused by injury or inflammation of nerves and often coexists with somatic or visceral pain. It may be described as burning, lancing, electric, numb, radiating, shooting, stabbing, tingling, heat or hypersensitive skin. This pain can be radicular (from single or multiple nerve roots) such as with herpes zoster and sciatica or stocking-glove (fingers and toes) such as with diabetes or chemotherapy-induced neuropathy.

ASSESSMENT QUESTION EXAMPLES

Ask questions like:

Does the pain vary with time of day?
Is your pain worse in certain positions?
Do certain activites make it better or worse?
How long does it last?

Use the same pain scale for the same patient in the same way at every visit (i.e. Wong-Baker Faces Pain Rating Scale or the 0-10 Numeric Pain Intensity Scale)

Opiods:

Moderate to severe pain and is effective across all 3 pain types (somatic, visceral and neuropathic).

Mainstay for treatment of moderate to severe cancer pain.

Can be used in combination with acetaminophen and/or NSAIDS

Examples: Codeine, Morphine, Norco, Fentanyl, Tramadol

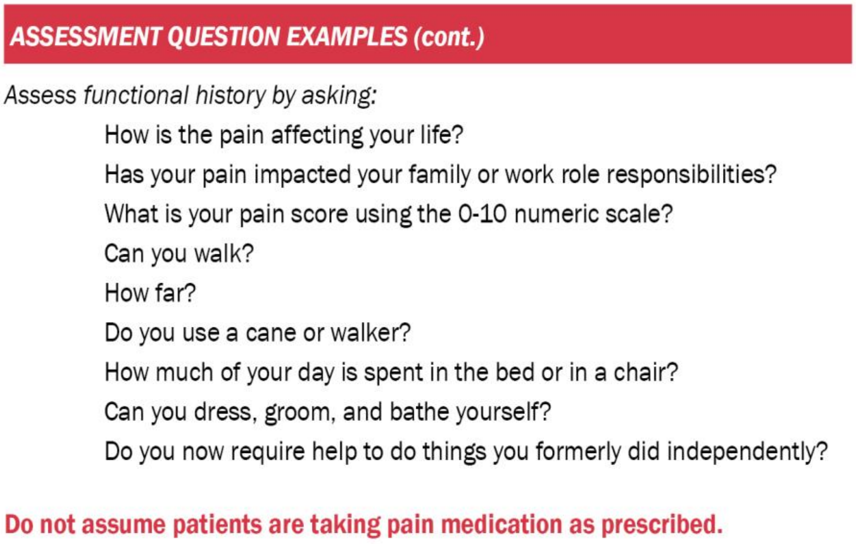
Corticosteroids:

Moderate to severe somatic and visceral pain.

Widely used as a multipurpose analgesic including bone pain, capsular pain (e.g. liver capsular stretch pain), headache (raised intracranial pressure), bowel obstruction (due to tumor compression). Evidence supports use for improved appetite, well-being and fatigue.

Can be used in combination with other synergistic drugs.

Examples: Dexamethasone, Prednisone

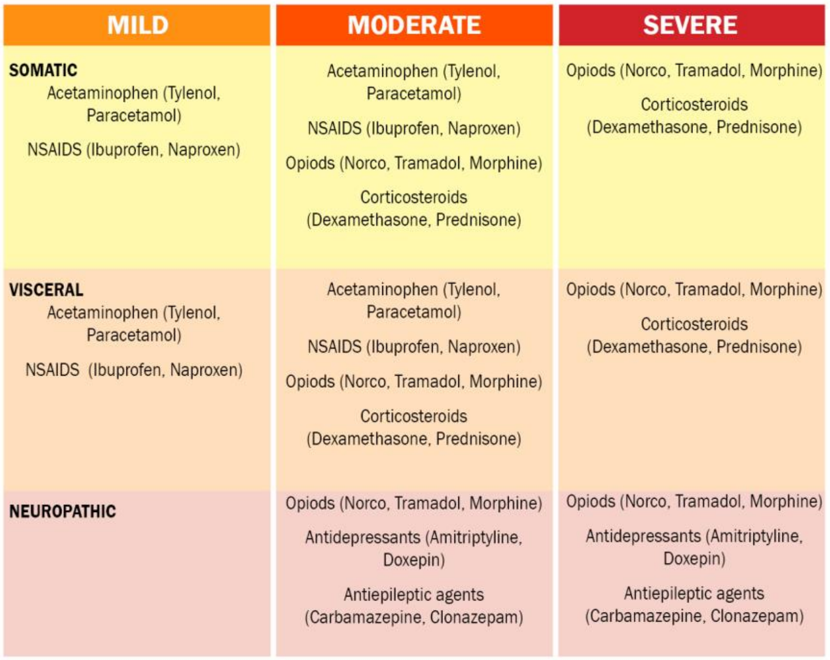


ASSESSMENT QUESTION EXAMPLES (cont.)

Assess functional history by asking:

How is the pain affecting your life?
Has your pain impacted your family or work role responsibilities?
What is your pain score using the 0-10 numeric scale?
Can you walk?
How far?
Do you use a cane or walker?
How much of your day is spent in the bed or in a chair?
Can you dress, groom, and bathe yourself?
Do you now require help to do things you formerly did independently?

Do not assume patients are taking pain medication as prescribed.



MILD	MODERATE	SEVERE
SOMATIC Acetaminophen (Tylenol, Paracetamol) NSAIDS (Ibuprofen, Naproxen)	Acetaminophen (Tylenol, Paracetamol) NSAIDS (Ibuprofen, Naproxen) Opiods (Norco, Tramadol, Morphine) Corticosteroids (Dexamethasone, Prednisone)	Opiods (Norco, Tramadol, Morphine) Corticosteroids (Dexamethasone, Prednisone)
VISCERAL Acetaminophen (Tylenol, Paracetamol) NSAIDS (Ibuprofen, Naproxen)	Acetaminophen (Tylenol, Paracetamol) NSAIDS (Ibuprofen, Naproxen) Opiods (Norco, Tramadol, Morphine) Corticosteroids (Dexamethasone, Prednisone)	Opiods (Norco, Tramadol, Morphine) Corticosteroids (Dexamethasone, Prednisone)
NEUROPATHIC	Opiods (Norco, Tramadol, Morphine) Antidepressants (Amitriptyline, Doxepin) Antiepileptic agents (Carbamazepine, Clonazepam)	Opiods (Norco, Tramadol, Morphine) Antidepressants (Amitriptyline, Doxepin) Antiepileptic agents (Carbamazepine, Clonazepam)

Information gathered from Center to Advance Pallitive Training Curriculum at www.capc.org