An Interprofessional Approach to Holistic End-of-Life Care in the Long-Term Care Setting

THE UNIVERSITY OF IOWA COLLEGE OF NURSING
Barbara and Richard Csomay Center for Gerontological Excellence

AUTHORS:

Candace C. Harrington, PhD, DNP, AGPCNP-BC, CDP

Andrew Aschbacher, DNP, APRN, FNP-C

Angela L. Flint, DNP, APRN, FNP-C, AGPCNP-BC

EDITOR:

Ryleigh M. M. Maas, BS

The University of Iowa College of Nursing
CSOMAY Center for Gerontological Excellence

An Interprofessional Approach to Holistic End-of-Life Care in the Long-Term Care Setting

TABLE OF CONTENTS

	Page
Scheme for Grading the Strength and Consistency of Evidence in the Guideline	2
Evidenced-Based Guideline	
A. Introduction	3
B. Purpose	4
C. Definitions of Key Terms	4
D. Individuals at Risk	4
E. Assessment Criteria	5
F. Assessment Tools, Instruments, and Forms	5
G. Description of the Practice	5
H. Assessment and Key Recommendations	7
I. Nursing Interventions Classification (NIC)	11
J. Nursing Outcomes Classification (NOC)	12
K. Guideline Implementation Process	13
L. Evaluation of Process and Outcomes	13
I. Appendices	
Appendix A. Assessment Tools	14
A.1. FICA Spiritual History Tool	15
A.2. Short Warwick Edinburgh Mental Well-being Scale	17
A.3. Pain Assessment in Advanced Dementia	19
A.4. Numerical Pain Rating Scale	21
A.5. Constipation Assessment Scale	22
A.6. Modified Borg Dyspnea Scale	23
A.7. Victoria Respiratory Congestion Scale	24
Appendix B. Guideline Implementation Process	25
B.1. Guideline Implementation Method	26
B.2. The Iowa Model Revised: Evidence-based Practice to Promote Excellence in Health Care©	27
B.3. Implementation Strategies for Evidence-Based Practice	28
Appendix C. SBAR Communication Form	29
Appendix D. LTC Resident Value Checklist	31
Appendix E. Knowledge Assessment Test	35
Appendix F. EOL Care in LTC Facilities Evaluation Monitor	38
Appendix G. EOL Care in LTC Facilities Outcome Monitor	40
Appendix H. Non-Pharmacologic Approach to Care	44
References	45
Contact Resources	47

Grading of Recommendations Assessment, Development, and Evaluation (GRADE)

This guideline was developed from an exhaustive literature review and synthesis of current evidence on identifying end-of-life care in long-term care facilities. Research and other evidence, such as guidelines and standards from professional organizations, were critiqued, analyzed, and used as supporting evidence.

The practice recommendations are assigned an evidence grade based upon the type and strength of evidence from research and other literature.

Scheme for grading the strength and consistency of evidence in the guideline:

A1 = Evidence from well-designed meta-analysis or well-done systematic review with results that consistently support a specific action (e.g., assessment, intervention, or treatment)

A2 = Evidence from one or more randomized controlled trials with consistent results

B1 = Evidence from high quality Evidence-Based practice guideline

B2 = Evidence from one or more quasi experimental studies with consistent results

C1 = Evidence from observational studies with consistent results (e.g., correlational, descriptive studies)

C2 = Inconsistent evidence from observational studies or controlled trials

D = Evidence from expert opinion, multiple case reports, or national consensus reports

Introduction

Despite the known benefits of early palliative care implementation, significant gaps remain in ensuring residents and their family members receive compassionate, high-quality end-of-life care (HQEOLC) that preserves their dignity (Coyle, 2015; Institute of Medicine [IOM], 2015; Temkin-Greener, Li, Li, Segelman, & Mukamel, 2016). As the U.S. population's life span increases, the number of older adults living with comorbid medical conditions is proportionately increasing. These comorbid conditions often lead to functional limitations and increased care dependency. This, in combination with evolving family dynamics and smaller nuclear families, leads to heightened long-term care (LTC) facility use at the end-of-life (EOL) (IOM, 2015; Temkin-Greener et al., 2016; Pivodic et al., 2018). Despite the growing number of individuals utilizing nursing homes, the suboptimal palliative care interventions often lead to underassessed and undertreated pain and other physical symptoms, emotional distress, limited spiritual support, aggressive treatments, burdensome transitions, and reduced family satisfaction (Gonella, Basso, Marinis, Campagna, & Giulio, 2019; Temkin-Greener et al., 2016; Carpenter, Lam, Ritter, & Ersek, 2020).

A systematic approach was used to search for the most relevant evidence to support this clinical practice guideline (CPG). An exhaustive search was conducted utilizing PubMed, EBSCO, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Good Scholar. The following search terms were used to navigate the literature: nursing homes OR long-term care AND end-of-life OR palliative care. Search of MeSH database included: ("nursing homes" OR "long term care") AND ("end of life care" OR "palliative care"). Time periods searched were between 2015 and 2020. Article selection was restricted to include only those meeting the following criteria: English language, published between the years 2015 and 2020, items with abstracts and free full text, peer-reviewed articles, and articles published in the United States.

Throughout the literature, commonly recurring themes support integrating specific interventions necessary to achieve HQEOLC (Gonella et al., 2019; Temkin-Greener et al., 2016). These four key domains include structure and processes of care, physical aspects of care, psychological and psychosocial aspects of care, and spiritual aspects of care (Kolb, Snowden, & Stevens, 2018; Gonella et al., 2019; Ferrell, Coyle, & Paice, 2018). Within the structure and processes of care lies the importance of an interdisciplinary palliative care team. This diverse care team should consist of long-term care (LTC) residents and their family members, managing providers (physicians, advanced practice registered nurses, and physician assistants), nurses (Director of Nursing, registered, and licensed practical nurses), certified nursing assistants, clinical pharmacists, ancillary health professionals including physical therapists and occupational therapists, social workers, registered dietitians, dietary services, and chaplains (Harrington, 2019). In addition, residents may receive care outside of the LTC setting from sources such as geriatricians, palliative care teams, and responsible health care providers who are valuable members of the interdisciplinary team (Harrington, 2019).

Purpose

The purpose of this clinical practice guideline (CPG) is to outline a systematic approach for the provision of high-quality end-of-life care (HQEOLC) among long-term care (LTC) residents and their support systems through an interprofessional care approach. This evidence-based CPG is intended for use by healthcare practitioners (physicians, nurse practitioners, and physician assistants), nurses (director of nursing, registered, and licensed practical nurses), certified nursing assistants, clinical pharmacists, ancillary health professionals including physical therapists and occupational therapists, social workers, nursing assistants, registered dietitians, dietary services, and chaplains (Harrington, 2019).

Definitions of Key Terms

- ***Long-Term Care*** **–** Skilled nursing facilities (SNF's) and intermediate care facilities. This term excludes individuals who reside in assisted living, communal housing, and those who are receiving short-term rehabilitation within skilled nursing facilities.
- ***End of Life Care / Hospice Care*** **–** End of life care, or hospice care, is implemented when a serious illness is no longer responding to medical attempts to cure or slow the disease progression. Hospice is provided when a provider believes that a terminal illness will lead to death within six months or less. Hospice care can be provided in two types of settings, at home or in a facility such as a nursing home, hospital, or a hospice center (NIA, 2021). Hospice interventions focus on relieving physical, spiritual, and emotional symptoms and encourage family participation in care provision.
- ***Palliative Care*** **–** Palliative care is specialized medical care focusing on providing patients with symptom management, psychosocial-spiritual care, and decision-making assistance. Palliative care can be implemented at any age, any stage of illness, and across numerous settings and is offered alongside curative treatments (NIA, 2021.

Individuals at Risk in Long-Term Care

This clinical practice guideline (CPG) is appropriate for residents and their support systems residing within long-term care (LTC) facilities. This population is often prone to multidimensional suffering, commonly presenting itself through physical symptoms, psychological and psychosocial symptoms, and spiritual distress. Resident views and preferences will be sought using an LTC Ombudsmen who will serve as a resident's advocate to ensure the CPG is consistent with culturally sensitive, resident-centered care. Every state is required to have an Ombudsman program that addresses complaints and advocates for improvements in the LTC system. The role of an LTC Ombudsman includes numerous responsibilities including educating LTC residents and their support systems of their rights, high-quality practices, and similar available services and resources; representation of resident interests before governmental agencies; seeking legal and administrative solutions to protect residents; advocating for changes to improve the quality of life (QOL) and care of LTC residents; and identifying, investigating, and resolving LTC resident complaints (Gadlin, 2007).

Assessment Criteria

Older adults who would most benefit from an end-of-life care (EOLC) practice guideline include those residing within long-term care (LTC) facilities. This clinical practice guideline (CPG) is appropriate for LTC residents 65 years of age or older who desire curative or life-prolonging treatments, or LTC residents who desire an EOL, comfort care approach.

Assessment Tools, Instruments, and Forms

Several assessment tools and forms are available to aid in the assessment of patients with a life-limiting disease or illness; however, no available tool meets all of the specific characteristic of residents in long-term care (LTC) facilities. After undergoing brief educational sessions, each member of the interdisciplinary team (IDT) will be able to assess LTC residents using each of the following tools:

- The FICA (Faith, Belief, or Meaning, Importance and Influence, Community, and Address/Action in Care) Spiritual History Tool (Appendix A.1) was designed to help structure questions for healthcare professionals who are taking a spiritual history in order to understand patients more fully (Puchalski, 2021).
- The Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS) (Appendix A.2) was adapted from the original 14-item scale designed to provide a full picture of mental wellbeing covering both mental and functional aspects of mental wellbeing (Fat et al., 2018).
- The Pain Assessment in Advanced Dementia (PAINAD) scale (Appendix A.3) is an objective pain assessment tool recommended to assist in assessing pain in this specific patient population. The PAINAD scale is a brief, 5-item tool assessing both physiological and psychological aspects of pain (Fry & Elliott, 2018). xx
- The Numerical Pain Rating Scale (NPRS) (Appendix A.4) provides a subjective assessment of physical pain in elderly individuals capable of expressing the severity of their pain (Alghadir et al., 2018).
- The Constipation Assessment Scale (CAS) (Appendix A.5) can assist healthcare providers in objectively assessing and differentiating between moderate and severe constipation (Economou, 2015).
- The Modified Borg Dyspnea Scale (Appendix A.6) is a subjective assessment tool that enables residents to rate their perceived breathlessness or difficulty breathing (Dudgeon, 2015).
- The Victoria Respiratory Congestion Scale (VRCS) (Appendix A.7) is a recently developed assessment tool that is clinically useful in determining the effectiveness of the treatment of respiratory secretions (Dudgeon, 2015).

Description of the Practice

Use of this end-of-life (EOL) clinical practice guideline is recommended during admission to a long-term care (LTC) facility and frequently throughout the resident's course of stay for those residents with a documented life-limiting illness. Before initiation of interventions, a goals of care discussion should be conducted between the interdisciplinary team (IDT) and the LTC resident and their family members. Furthermore, goals of care can change over time and should be readdressed throughout the care process.

Strengths and Limitations of the Evidence

The evidence was analyzed using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) system (Pg. 2). The GRADE system uses a seven-level scale for rating the quality of evidence. The findings across the evidence support the need for a multidisciplinary, holistic approach to enhance end-of-life (EOL) care.

Strengths of the evidence include retrospective data collection through proxy respondents, creating a feasible method for large-scale studies. This approach avoids potential bias inherent in prospective sampling caused by underrepresentation of people who live longer than the study follow-up period (Pivodic et al., 2018). That said, retrospective data collection may have been met by potential recall bias given the difficulty of remembering events in the past.

Limitations of the evidence include a broad range of search strategies for palliative care potentially limiting the number of captured relevant studies. Furthermore, many studies relied on a limited sample of respondents within each long-term care (LTC) facility due to cost restrictions.

In developing this CPG, the potential benefits, risks, and side effects of the guideline have been considered and include:

Benefits:

- Decreased burdensome transitions near the EOL
- Decreased use of aggressive interventions
- Facilitates resident-centered care (treatment goals, advanced care planning, preferences about life-sustaining treatment)
- Higher family satisfaction with care
- Greater control of symptoms (spiritual, emotional, and physical)

Risks:

- Emotionally challenging for providers to confront EOL issues
- Lack of knowledge regarding EOL care and engaging in EOL care discussions
- Negative misconceptions regarding palliative care interventions
- Residents and their support systems readiness to engage in EOL care discussions – potentially psychological distressing

Side Effects:

- Unintended pharmacological side effects including but not limited to constipation, diarrhea, nausea, vomiting, fatigue, drowsiness, and anticholinergic effects.

Procedure for Updating the CPG:

According to the University of Iowa College of Nursing Csomay Center for Gerontological Excellence, CPG's undergo revision every five years to ensure the guideline is current and up to date.

Facilitators and Barriers of the CPG:

Potential barriers may include LTC facility access to palliative care teams, adequate LTC staffing and high-turnover rate, the IDT's knowledge regarding high-quality EOL care, lack of education of CNA's, and LTC resident and family members willingness to participate in palliative care interventions.

Potential Resource Implications of Applying Recommendations

- Time involvement
- Adequate staffing
- Increased efficiency and management of care

Funding Body Influence and Competing Interests of CPG Group Members:

There are no external funding bodies or competing interests in the development of this CPG.

External Review of CPG:

The development of this CPG is undergoing review by five expert panelists representing different areas of expertise across the interprofessional team. This review process is done to establish CPG rigor. In evaluation phase one, a long-term care interprofessional expert consensus panel consisting of a palliative care physician, a nurse practitioner long-term care expert, a medical social worker, and a registered nurse. The group independently evaluated six domains of rigor of the clinical practice guideline using the *Appraisal of Guidelines for Research and Evaluation (AGREE) II* instrument to establish face and content validity. AGREE II 's 70% benchmark was exceeded after the first round (87.2%) with revisions based on expert panelist recommendations. In phase two, an anonymous electronic 10-question *Modified Practitioner Feedback Questionnaire (MPFQ*; α = .889) was distributed with the guideline using convenience and snowball sampling. Twenty-two long-term care professionals found the guideline acceptable with a 92.7% aggregate approval rate.

Assessment and Key Recommendations

Use of the FICA Spiritual History Tool

The FICA Spiritual History Tool is composed of four domains that address multiple components of spirituality. This tool is designed to help health care professionals address spiritual issues with patients in order to gain a better understanding of the patient. A member of the health care team should utilize this tool during a resident's initial admission to a long-term care (LTC) facility and during follow-up visits, as appropriate (Puchalski, 2021) *[Evidence Grade = A1]*.

Based upon information gathered from the FICA Spiritual Assessment Tool, healthcare providers can identify spiritual issues and make appropriate referrals to chaplains or to the resident's desired spiritual care provider. The healthcare team should utilize clinically trained chaplains as part of the interdisciplinary team (IDT) to provide LTC resident with patient-centered spiritual care and support (NIA, 2021;) *Evidence Grade = D]*).

The Short Warwick Edinburgh Mental Well-being Scale

The Short Warwick Edinburgh Mental Well-being Scale (SWEMWBS) is a shortened 7-item scale adapted from the original, 14-item mental wellbeing scale. These scales were developed to enable the measurement of mental wellbeing in the general population. Each item is worded positively and covers both feeling and functioning aspects of mental wellbeing.

The information garnered from the SWEMWBS should guide the healthcare team in determining the resident's current state of mental health. Since serious illness can influence overall wellbeing, the SWEMWBS can guide communication between the IDT, including the resident and their family members, in order to create a plan of care that meets the needs and goals of the resident. Scores of 17 or less represent probable depression or anxiety, scores of 18-20 suggest possible depression or anxiety, score of 21-27 indicate average mental wellbeing, and scores of 28 and above indicate high mental wellbeing. IDT members should listen attentively, reflect the resident's thought and feelings, and offer a plan to address areas of support. Often, emotional distress is linked to physical distress and care should begin with providing best practice symptom management (BC Centre for Palliative Care, 2017 *[Evidence Grade = D]*. Appropriate referrals should be made to meet the identified needs of the resident, including but not limited to social workers, caregiver service options and support, counseling, spiritual health professionals, and financial resources as these can all contribute to psychosocial distress (BC Centre for palliative Care, 2017 *[Evidence Grade = D]*.

PAINAD

The PAINAD scale is a brief five-item observational tool used to assess pain in patients with advanced dementia. This scale assesses physiological and psychological aspects of pain and has been shown to be a reliable indicator of pain intensity in people with cognitive impairments (Fry & Elliott, 2018) *[Evidence Grade = A1]*. The interdisciplinary team should measure resident pain using the PAINAD scale upon admission to the LTC facility, after the administration of an analgesic or nonpharmacologic intervention, during any change in condition, and at follow-up visits, as appropriate.

Controlling pain is an important aspect of palliative care to improve quality of life. The PAINAD should guide the IDT in making necessary steps to address pain at the end-of-life. Scores of 1-3 indicate mild pain; 4-6 indicate moderate pain; and 7-10 indicate severe pain. Depending on the resident's goals of care, initial first steps may include immediate referral to an acute care setting in the event of an emergent situation. Interventions should consist of both nonpharmacologic and pharmacologic approaches. Nonpharmacologic approaches may be implemented by any member of the IDT and include but are not limited to therapeutic massage, repositioning, thermotherapy, and deep breathing

exercises, among others. Pharmacologic intervention should correspond to the severity of pain, the type of pain, and the resident's goals of care. Treatment should utilize a stepwise approach beginning with acetaminophen (for pain rating of 1-3), then moving to acetaminophen in combination with opioids (for pain rating between 4 and 6), and lastly moving to stronger opioids (for pain rating of 7-10) (BC Centre for Palliative Care, 2017) *[Evidence Grade = D]*.

The NPRS

Numerical rating scales (NRS's) are the most commonly used scales to assess pain given their simplicity, reproducibility, and sensitivity to changes in pain. The NPRS is an 11-point Likert scale scored from 0 to 10. A score of 0 indicates no pain and a score of 10 indicates the worst pain imaginable. LTC residents are to verbally select a value between 0 and 10 that most represents the intensity of their pain. The NPRS should be administered at the initial visit with a LTC resident, during any change in condition, after the administration of an analgesic or nonpharmacologic intervention, and during subsequent follow-up visits, as appropriate.

Refer to PAINAD section for interventions for physical pain.

The CAS

The CAS is designed to assist healthcare providers in objectively assessing and differentiating between moderate and severe constipation. The CAS consists of eight constipation-related symptoms scored on a scale of 0 (no problem) to 2 (severe problem) (Molin et al., 2012) *[Evidence Grade = A1]*. A member of the healthcare team should complete this scale upon admission to gather baseline data, after pharmacologic or nonpharmacologic interventions for constipation, and frequently throughout the course of care, paying particular attention to those residents receiving opioid pain medications.

Constipation is often multifactorial throughout the end-of-life process. Opioids are often a significant cause of constipation and should be consider as a potential contributing factor. Depending on the severity of the constipation as determined by the CAS, intervention should include both a nonpharmacologic and a pharmacologic approach. Nonpharmacologic interventions include hydration, adequate fiber intake, promotion of privacy and independence, and mobility, as tolerated. Pharmacologic measures include the use of oral stool softeners and laxatives. Rectal interventions include suppositories, enemas, and manual extraction but should be used infrequently (BC Centre for Palliative Care, 2017 *[Evidence Grade = D]*. These recommendations are meant to supplement existing bowel protocols previously in place throughout U.S. nursing homes.

The Modified Borg Dyspnea Scale

The Modified Borg Dyspnea Scale is a 12-item assessment tool designed to assist patients in rating their breathing difficulty. Scores range from 0 (no dyspnea at all) to 10 (maximal breathing difficulty). A member of the health care team should assess for dyspnea upon admission to the LTC facility, after pharmacologic or nonpharmacologic interventions for dyspnea, and at follow up visits, as appropriate (Dudgeon, 2015) *[Evidence Grade = A1]*.

Management of dyspnea should be guided by the resident's goals and preferences, the severity of the disease, the benefits and risks, and the overall prognosis of care. If indicated, initial steps may include assessing for infection, checking renal function and electrolytes, oxygen saturation, and a chest radiograph. Treatment should be done utilizing both nonpharmacologic and pharmacologic interventions. Nonpharmacologic approaches to dyspnea include but are not limited to upright positioning, the use of certain breathing exercises, relaxation and guided imagery, fans to promote airflow, therapeutic touch, among others. Pharmacologic interventions primarily consist of administration of O2 via nasal cannula, oral or parenteral opioids, bronchodilators, anxiolytics, and corticosteroids (BC Center for Palliative Care, 2017) *[Evidence Grade = D]*.

The VRCS

The VRCS was designed to assist healthcare providers in assessing for respiratory congestion in end-of-life care, commonly referred to as the death rattle. This scale assists healthcare providers in rating resident congestion on a scale of 0 to 3. The health care team should assess for respiratory congestion frequently throughout the end-of-life process and after nonpharmacologic or pharmacologic interventions for congestion (Dudgeon, 2015) *[Evidence Grade = A1]*.

A score of 1 or greater indicates the presence of respiratory congestion and should lead to interventions by the IDT. Utilizing both nonpharmacological and pharmacological interventions can provide the greatest relief of symptoms if initiated promptly. Nonpharmacological interventions can be done by any member of the IDT and consist of frequent oral care, humidifying the resident's room, repositioning to promote drainage of secretions, and utilizing suction when appropriate. Pharmacological interventions should be administered upon the first sign of audible congestion and should include the use of anticholinergic medications (BC Center for Palliative Care, 2017) *[Evidence Grade = D]*.

Nursing Interventions Classification (NIC)

"The Nursing Interventions Classification (NIC) is a comprehensive standardized classification of interventions that nurses perform. The Classification includes the interventions that nurses do on behalf of patients, both independent and collaborative interventions, both direct and indirect care. An *intervention* is defined as *any treatment, based upon clinical judgment and knowledge, which a nurse performs to enhance patient/client outcomes*. NIC can be used in all settings (from acute care to intensive care units, to home care, to hospice, to primary care) and all specialties (from critical care nursing to pediatric nursing and gerontological nursing) (Butcher, Bulechek, Dochterman, & Wagner, 2018).

Planning care and services using nursing standardized languages begins with assessment to generate accurate nursing diagnoses. For the *Interprofessional Approach to Holistic End-of-Life Care in Long Term Care Facilities* guideline, some of the nursing diagnoses that are particularly relevant are Anxiety, Acute Pain, Impaired Comfort, Ineffective Breathing Pattern, Risk for Dry Mouth, Risk for Constipation, Risk for Compromised Human Dignity, Readiness for Enhanced Spiritual Wellbeing, Risk for Spiritual Distress, Readiness for Enhanced Family Coping, Risk for Loneliness, and Deficient Knowledge. Selected nursing interventions from the Nursing Interventions Classification (NIC) and outcomes from the Nursing Outcomes Classification (NOC) are listed to illustrate the process of clinical reasoning when assessing elders at risk for suboptimal end-of-life care in the LTC setting. The listed interventions and outcomes are intended to serve as examples, and not as an exhaustive list.

Major Intervention

These are the obvious intervention(s) associated with the guideline. They were selected because they provide a good match with the focus of the guideline.

1800 Self-Care Assistance: Assisting another to perform activities of daily living

1850 Sleep Enhancement: Facilitation of regular sleep/wake cycles

2080 Fluid/Electrolyte Management: Regulation and prevention of complications from altered fluid and/or electrolyte levels

3350 Respiratory Monitoring: Collection and analysis of patient data to ensure airway patency and adequate gas exchange.

4410 Mutual Goal Setting: Collaborating with patient to identify and prioritize care goals, then developing a plan for achieving those goals.

5230 Coping Enhancement: Assisting a patient to adapt to perceived stressors, changes, or threats that interfere with meeting life demands and roles

5250 Decision-making support: Providing information and support for a patient who is making a decision regarding health care

5270 Emotional support: Provision of reassurance, acceptance, and encouragement during times of stress

5515 Health Literacy Enhancement: Assisting individuals with limited ability to obtain, process, and understand information related to health and illness

5602 Teaching: Disease Process: Assisting the patient to understand information related to a specific disease process.

6490 Fall Prevention: Instituting special precautions with patient at risk for injury from falling

6610 Risk Identification: Analysis of potential risk factors, determination of health risks, and prioritization of risk reduction strategies for an individual or group.

6650 Surveillance: Purposeful and ongoing acquisition, interpretation, and synthesis of patient data for clinical decision-making

6680 Vital Signs Monitoring: Collection and analysis of cardiovascular, respiratory, and body temperature data to determine and prevent complications

7800 Quality Monitoring: Systematic collection and analysis of an organization's quality indicators for improving patient care

Nursing Outcomes Classification (NOC)

The Nursing Outcomes Classification (NOC) is a standardized classification of patient/client outcomes developed to evaluate the effects of nursing interventions. "A nursing-sensitive patient outcome is an individual, family, or community state, behavior or perception that is measured along a continuum in response to nursing intervention(s). The outcomes are variable concepts that can be measured along a continuum using a measurement scale(s). The outcomes are stated as concepts that reflect a patient, caregiver, family, or community state, behavior, or perception rather than as expected goals." (Moorhead, Swanson, Johnson, & Maas, 2018).

0004 Sleep: Natural periodic suspension of consciousness during which the body is restored

0300 Self-Care: Activities of Daily Living (ADL): Ability to perform the most basic physical tasks and personal care activities independently with or without assistive device

0306 Self-Care: Instrumental Activities of Daily Living (IADL): Ability to perform activities needed to function in the home or community independently with or without assistive device.

0415 Respiratory Status: Movement of air in and out of the lungs and exchange of carbon dioxide and oxygen at the alveolar level

1211 Anxiety Level: Severity of manifested apprehension, tension, or uneasiness arising from unidentifiable source

1300 Acceptance: Health Status: Reconciliation to significant change in health circumstances

1302 Coping: Personal actions to manage stressors that tax an individual's resources

1307 Dignified Life Closure: Personal actions to maintain control during approaching end of life

1308 Adaptation to Physical Disability

Adaptive response to a significant functional challenge due to a physical disability

2000 Quality of Life: Extent of positive perception of current life circumstances

2007 Comfortable Death: Physical, psychospiritual, sociocultural, and environmental ease with the impending end of life

2008 Comfort Status: Overall physical, psychospiritual, sociocultural, and environmental ease and safety of an individual

2103 Symptom Severity: Severity of perceived adverse changes in physical, emotional, and social functioning

2301 Medication Response: Therapeutic and adverse effects of prescribed medication

Guideline Implementation

Implementation of a practice guideline is a challenging step to achieving evidence-based practice. "The Iowa Model Revised: Evidenced-Based Practice to Promote Excellence in Health Care©" (Appendix B.2) is a valuable resource to organizations, nurse leaders, and individuals who are interested in implementing an EBP Guideline into practice. To assist readers in implementing this guideline we have included the Iowa Model© and a diagram that highlights a number EBP implementation strategies that can be used to implement this guideline into a practice setting. Details on the Iowa Model can be found in Evidence-based Practice in Action: Comprehensive Strategies, Tools, and Tips from the University of Iowa Hospital and Clinics (Cullen et al., 2018). Specific implementation tools can be found in Chapter 8: Implementation, including how to develop tools on how to develop Sound Bites, Journal Clubs, Posters, Education, Pocket Guides, Case Studies, Incentives, Checklists, Documentation, and Peer Influence. The "Implementation Strategy for Evidence-based Practice" in Appendix B.3 of this guideline includes a list of strategies the are explained in detail in the Evidence-based Practice in Action: Comprehensive Strategies, Tools, and Tips from the University of Iowa Hospital and Clinics (2018) textbook.

Evaluation of Process and Outcomes

Process Indicators

Process Indicators are those interpersonal and environmental factors that can facilitate the use of a guideline.

Outcome Indicators

Outcome indicators are those expected to change or improve from consistent use of the guideline. The major outcome indicators that should be monitored over time are:

- Spiritual wellbeing
- Mental wellbeing
- Symptom management (pain, constipation, dyspnea, secretions)
- Transitions of care or hospitalizations
- Use of MOST, MOLST, POST, and POLST

Appendix A

Holistic End-of-Life Care Assessment Tools

Appendix A contains examples of assessment tools, instruments, and forms to use in patient assessment of holistic end-of-life care. The purpose and instructions for use accompany each tool or form. Tools, instruments, and forms in Appendix A are:

- Appendix A.1: FICA Spiritual History Tool
- Appendix A.2: Short Warwick Edinburgh Mental Well-being Scale
- Appendix A.3: Pain Assessment in Advanced Dementia
- Appendix A.4: Numerical Pain Rating Scale
- Appendix A.5: Constipation Assessment Scale
- Appendix A.6: Modified Borg Dyspnea Scale
- Appendix A.7: Victoria Respiratory Congestion Scale

Appendix A.1

FICA Spiritual History tool

Purpose: The FICA Spiritual History Tool was designed to assist health care professionals with addressing spiritual issues with patients. A spiritual history should be taken as part of the initial visit with a patient but can also be done as part of follow-up visits, as appropriate (Puchalski, 2021). The FICA Spiritual History Tool has been validated and proven to be feasible for the clinical assessment of spirituality, (Borneman, 2018). This tool has a high internal consistency with a Cronbach's alpha of 0.77 to 0.89 among the four domains (Borneman, 2018).

Instructions: The FICA Spiritual History Tool contains four domains. Within each domain are a set of questions, for a total of 11 open-ended individual responses. A member of the health care team should ask each of the 11 questions, recording the resident's responses to each. Throughout the assessment, the provider should respect the resident's privacy regarding spiritual beliefs and refrain from imposing their beliefs on the resident. If appropriate, the health care professional should refer the resident to a chaplain, spiritual advisor, or a community resource.

Appendix A.1

FICA Spiritual History tool

FICA Spiritual History Tool©*

The acronym FICA can help to structure questions for healthcare professionals who are taking a spiritual history.

***

F – Faith, Belief, Meaning

"Do you consider yourself to be spiritual?" or "Is spirituality something important to you?"
"Do you have spiritual beliefs, practices, or values that help you to cope with stress, difficult times, or what you are going through right now?"
"What gives your life meaning?"

I – Importance and Influence

"What importance does spirituality have in your life?"
"Has your spirituality influenced how you take care of yourself, particularly regarding your health?"
"Does your spirituality affect your healthcare decision making?

C – Community

"Are you part of a spiritual community?"
"Is your community of support to you and how?" For people who don't identify with a community consider asking "Is there a group of people you really love or who are important to you?"
*(Communities such as churches, temples, mosques, family, groups of like-minded friends, or yoga or similar groups can serve as strong support systems for some patient*s.)

A - Address/Action in Care

"How would you like me, as your healthcare provider, to address spiritual issues in your healthcare?"
(With newer models, including the diagnosis of spiritual distress, "A" also refers to the "Assessment and Plan" for patient spiritual distress, needs and or resources within a treatment or care plan.

© Copyright Christina Puchalski, MD, and The George Washington University 1996 (updated 2021). All rights reserved.
* Adapted from: Puchalski, C., & Romer, A. L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of palliative medicine*, *3*(1), 129-137.

Appendix A.2

Short Warwick Edinburgh mental well-being scale

Purpose: The Short Warwick Edinburgh Mental Well-being Scale (SWEMWBS) is a shortened 7-item scale adapted from the original, 14-item WEMWBS. This scale was designed to provide a picture of mental wellbeing, covering both feeling and functioning aspects of mental wellbeing. Neither of the two scale were developed to monitor change at the individual level or within clinical settings, however, both have been shown to be responsive to individual change and have been used by providers to help patients think about their mental health ((Fry & Elliott, 2018).).

Instructions: The 7-items in the SWEMWBS carry more weight and superior scaling properties compared to the 14 items in the original version. Performing the SWEMWBS should be done by a health care provider upon resident admission to a LTC facility and at follow-up visits, as appropriate. The 7-item scale contains seven questions which are rated on a 5-point Likert scale, with higher scores indicating positive mental wellbeing. Scores are then summed to obtain a total score, ranging from 7 to 35. In order to compare results of the 7-item scale to other studies, raw scores need to be converted using a conversion table provided by the Warwick Medical School (Fry & Elliott, 2018). ().

SHORT WARWICK EDINBURGH MENTAL WELL-BEING SCALE

Instructions: below are some statements about feelings and thoughts. Please select the answer that best describes your experience of each over the last 12 weeks.

	None of the time	Rarely	Some of the time	Often	All of the time
1. I've been feeling optimistic about the future	1	2	3	4	5
2. I've been feeling useful	1	2	3	4	5
3. I've been feeling relaxed	1	2	3	4	5
4. I've been dealing with problems well	1	2	3	4	5
5. I've been thinking clearly	1	2	3	4	5
6. I've been feeling close to other people	1	2	3	4	5
7. I've been about to make up my own mind about things	1	2	3	4	5

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) © University of Warwick 2006, all rights reserved.

Appendix A.3

Pain Assessment in Advanced Dementia Scale (PAINAD)

Purpose: The PAINAD scale is a 5-item tool designed to assist health care professionals in assessing pain in patients with advanced dementia. This scale provides a picture of both physiological and psychological pain.

Instructions: The PAINAD scale consists of five domains which are scored on a 3-point scale. Total scores range from 0-10, with mild pain being 1-3, moderate being 4-6, and severe pain ranging between 7-10 (Warden et al., 2003). A member of the health care team should observe the resident for at least five minutes before scoring their behavior. The assessment domains consist of breathing, vocalization, facial expression, body language, and consolability. Residents should be assessed at the time of admission and at follow-up visits, as appropriate.

Scoring: Add the score for each item to achieve a total score. Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score suggesting more severe pain (0= "no pain" to 10= "severe pain").

After each use, compare the total score to the previous score received. An increased score suggests an increase in pain, while a lower score suggests pain is decreased.

NOTE: Behavior observation scores should be considered alongside knowledge of existing painful conditions and reports from someone who knows the older adult (like a family member or nursing assistant) and their pain behaviors. Remember some older adults may not demonstrate obvious pain behaviors or cues.

Permission has been obtained for copying the tools if used for clinical purposes of improving pain care in your organization.

Warden, V, Hurley AC, Volicer, V. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. J Am Med Dir Assoc, 4:9-15. Developed at the New England Geriatric Research Education & Clinical Center, Bedford VAMC, MA.

Pain Assessment in Advanced Dementia Scale (PAINAD)

Items	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low- level of speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimacing	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	

Total Score: _____

***** Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0 = “no pain” to 10 = “severe pain”).

Appendix A.4

Numerical Pain Rating Scale

Purpose: The NPRS is an 11-point numerical scale designed to assess pain intensity in individuals of all ages.

Instructions: The NPRS contains an 11-point scale. Scores range from 0-10, with 0 indicating no pain, and 10 indicating the worst pain imaginable. A member of the interdisciplinary team should ask the LTC resident to rate their pain along this numerical scale at the time of admission, after administration of an analgesic or nonpharmacologic intervention, and at follow-up visits, as appropriate.

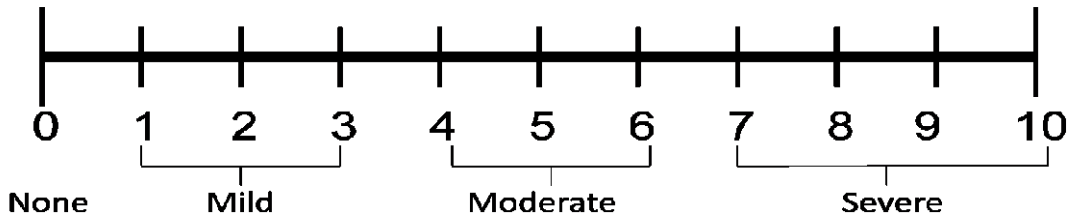
General Information

- The patient is asked to make three pain ratings, corresponding to current, best and worst pain experienced over the past 24 hours.
- The average of the 3 ratings was used to represent the patient's level of pain over the previous 24 hours

Patient Information

- "Please indicate the intensity of current, past, best, and worst pain levels over the past 24 hours on a scale of 0 (no pain) to 10 (worst pain imaginable)"

McCaffery, M., Beebe, A., et al. (1989). Pain: Clinical manual for nursing practice, Mosby St. Louis, MO.



Appendix A.5

Constipation Assessment Scale

Purpose: The CAS was designed to assist healthcare providers in assessing the severity of constipation.

Instructions: The CAS measures eight constipation-related symptoms during the past three days on a scale of 0 to 2. A score of 0 indicates no problem and a score of 2 in indicates a severe problem. The assessing healthcare team member should ask the resident to rate each of the eight symptoms and circle the corresponding answer.

Items	No Problem	Some Problem	Severe Problem
1. Abdominal distension or bloating	0	1	2
2. *Change in amount of gas passed rectally*	0	1	2
3. *Less frequent bowel movement*	0	1	2
4. *Oozing liquid stool*	0	1	2
5. *Rectal fullness or pressure*	0	1	2
6. *Rectal pain with bowel movement*	0	1	2
7. *Smaller tool size*	0	1	2
8. *Urge but inability to pass stool*	0	1	2

Patient's Name: Date:

Appendix A.6

Modified Borg Dyspnea Scale

Purpose: The Modified Borg Dyspnea Scale was designed to provide patient's and healthcare providers a way of measuring and assessing dyspnea.

Instructions: The NPRS contains an 11-point scale. Scores range from 0-10, with 0 indicating no difficulty, and 10 indicating maximal dyspnea. A member of the healthcare team should ask the resident to rate the difficulty of their breathing and circle the numeric response.

0	Nothing at all
0.5	Very, very slight (just noticeable)
1	Very slight
2	Slight
3	Moderate
4	Somewhat severe
5	Severe
6	
7	Very Severe
8	
9	Very, very severe (almost maximal)
10	Maximal

Modified borg dyspnea scale. (n.d.). Lung Foundation Australia. Retrieved April 10, 2021, from https://pulmonaryrehab.com.au/~resources/02_Patient_assessment/04_modified_borg_dyspnoea_scale.pdf

Appendix A.7

Victoria Respiratory Congestion Scale

Purpose: The VRCS is a 4-item assessment scale designed to assist healthcare professionals in classifying the intensity of a resident's respiratory congestion, commonly referred to as the death rattle.

Instructions: The VRCS measures audible congestion on a scale of 0 to 3. A score of 0 indicates no audible congestion is present. A score of 3 indicates the presence of congestion that can be heard from the doorway of the resident's room. The healthcare team member should begin the assessment standing near the resident's chest and listen for several breaths. The member should then listen for several breaths standing at the foot of the resident's room followed by several breaths at the door of the resident's room.

Please visit the Victoria Hospice website here for a sample of the VRCS.

Victoria Hospice Society. (2006). *Victoria Respiratory Congestion Scale (VRCS).* Medical care of the dying, 4th ed.

Appendix B

GUIDELINE IMPLEMENTATION FORM

Appendix B contains tools to assist in implementing this guideline into practice. These tools include:

- **Appendix B.1:** Guideline Implementation Form
- **Appendix B.2:** The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care©
- **Appendix B.3:** Implementation Strategies for Evidence-Based Practice

Appendix B.1

GUIDELINE IMPLEMENTATION FORM

Target Audience: Facility Staff, Direct Caregivers/ Nursing Assistants, and Family Members

Class (20 minutes each)	Content	Learning Activities

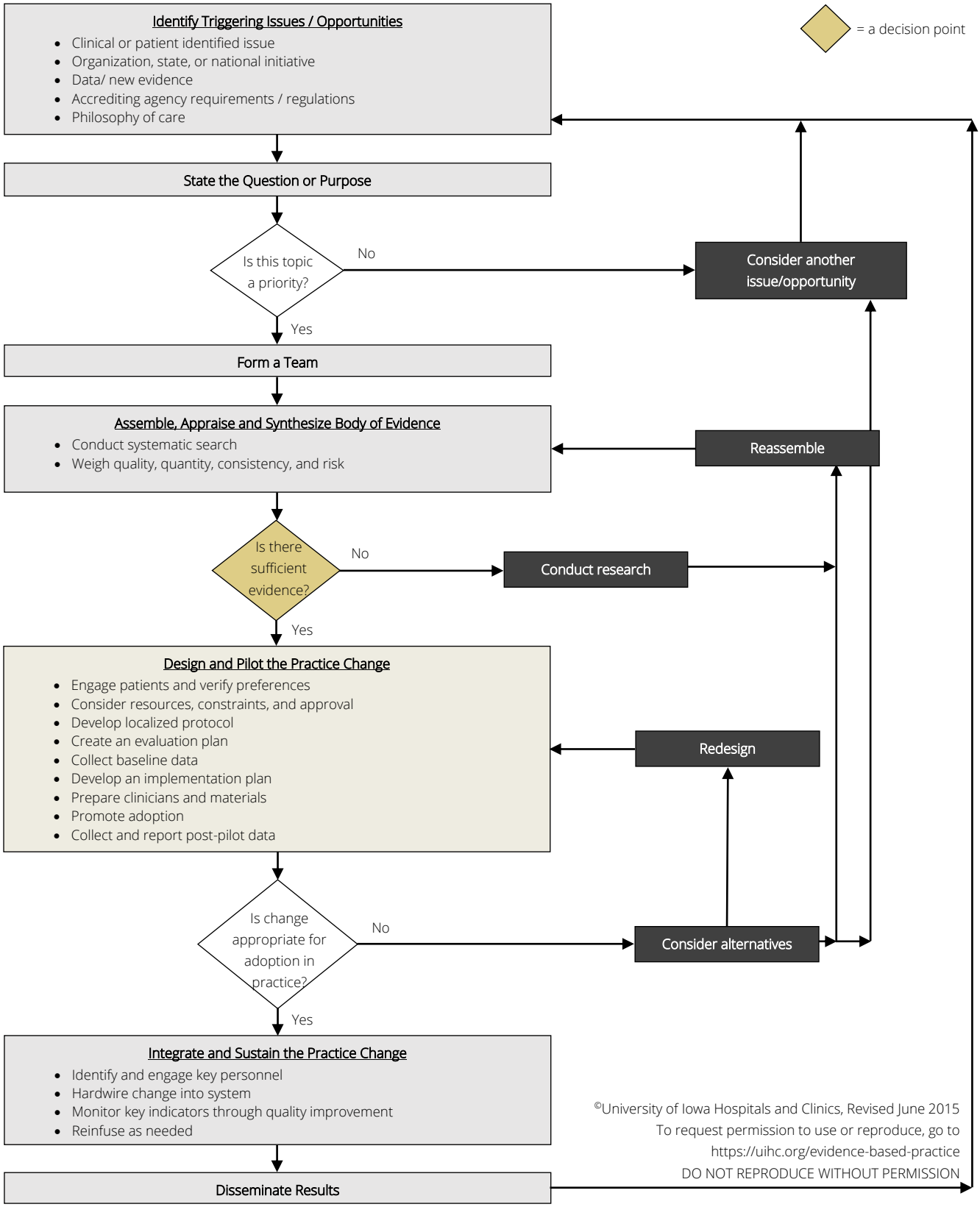
Class 1
End-of-Life Care:
A simple overview
	What are the differences / similarities between palliative and hospice care?
	
	Discuss the benefits of an interprofessional approach to end-of-life care
	
	Identify the four key domains of high-quality end-of-life care
	
	• What is SBAR (Appendix C)
	  ▪ S=Situation (a concise statement of the problem)
	  ▪ B=Background (pertinent and brief information related to the situation)
	  ▪ A=Assessment (analysis and considerations of options — what you found/think)
	  ▪ R=Recommendation (action requested or recommended — what you want)
		Images and pictures with group discussion
		• Available tools to assess LTC resident's

Class 2
End-of-Life Care:
The CNA's role
	• Review of Class 1 content
	  ▪ Early Recognition and Reporting Makes a Difference! *SBAR*
	  ▪ Role of the CNA working with terminally ill LTC residents
	  ▪ Review of Discussion of non-pharmacologic interventions for symptom relief at the EOL
		Images and pictures with group discussion
		  ▪ Hands-on learning
		  ▪ SBAR toolkit
		  ▪ Oral care, resident positioning

Class 3 Holistic EOL Care: Putting it all together	• Review of Class 1 • Review of Class 2 • Case Scenarios "What should I do?" • Reiteration of ***SBAR***	• Images and pictures • Group discussion

Appendix B.2

The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care©



©University of Iowa Hospitals and Clinics, Revised June 2015
To request permission to use or reproduce, go to
https://uihc.org/evidence-based-practice
DO NOT REPRODUCE WITHOUT PERMISSION

Appendix B.3

Implementation Strategies for Evidence-Based Practice

	Create Awareness & Interest	Build Knowledge & Commitment	Promote Action & Adoption	Pursue Integration & Sustained Use
Connecting with Clinicians, Organizational Leaders and Key Stakeholders	• Highlight advantages* or anticipated impact* • Highlight compatibility* • Continuing education programs* • Sound bites* • Journal club* • Slogans & logos • Staff meetings • Unit newsletter • Unit in-services • Distribute key evidence • Posters and postings/ fliers • Mobile 'show on the road' • Announcements & broadcasts	• Education (e.g., live, virtual or computer-based)* • Pocket guides • Link practice change & power holder/stakeholder priorities* • Change agents (e.g., change champion*, core group*, opinion leader*, thought leader, etc.) • Educational outreach or academic detailing* • Integrate practice change with other EBP protocols* • Disseminate credible evidence with clear implications for practice* • Make impact observable* • Gap assessment/gap analysis* • Clinician input* • Local adaptation* & simplify* • Focus groups for planning change* • Match practice change with resources & equipment • Resource manual or materials (i.e., electronic or hard copy) • Case studies	• Educational outreach/academic detailing* • Reminders or practice prompts* • Demonstrate workflow or decision algorithm • Resource materials and quick reference guides • Skill competence* • Give evaluation results to colleagues* • Incentives* • Try the practice change* • Multidisciplinary discussion & troubleshooting • "Elevator speech" • Data collection by clinicians • Report progress & updates • Change agents (e.g., change champion*, core group*, opinion leader*, thought leader, etc.) • Role model* • Troubleshooting at the point of care/ bedside • Provide recognition at the point of care*	• Celebrate local unit progress* • Individualize data feedback* • Public recognition* • Personalize the message to staff (e.g., reduces work, reduces infection exposure) based on actual improvement data • Share protocol revisions with clinician that are based on feedback from clinicians, patient or family • Peer influence • Update practice reminders
Building Organizational System Support	• Knowledge broker(s) • Senior executives' announcements • Publicize new equipment	• Teamwork* • Troubleshoot use/ application* • Benchmark data* • Inform organizational leaders* • Report within organizational infrastructure* • Action plan* • Report to senior leaders	• Audit key indicators* • Actionable and timely data feedback* • Non-punitive discussion of results* • Checklist* • Documentation* • Standing orders* • Patient reminders* • Patient decision aides* • Rounding by unit & organizational leadership* • Report into quality improvement program* • Report to senior leaders • Action plan* • Link to patient/ family needs & organizational priorities • Unit orientation • Individual performance evaluation	• Audit and feedback* • Report to senior leaders* • Report into quality improvement program* • Revise policy, procedure or protocol* • Competency metric for discontinuing training • Project responsibility in unit or organizational committee • Strategic plan* • Trend results* • Present in educational programs • Annual report • Financial incentives* • Individual performance evaluation

* = Implementation strategy is supported by at least some empirical evidence in healthcare

©University of Iowa Hospitals and Clinics, Revised June 2015
To request permission to use or reproduce, go to https://uihc.org/evidence-based-practice; DO NOT REPRODUCE WITHOUT PERMISSION

Source: Cullen et al., 2018

Appendix C

SBAR FORM: INTERPROFESSIONAL TEAM COMMUNICATION

Instructions:

1. Use this tool when giving a verbal or written report. It is not the patient's medical record.
2. Attach a current medication list
3. Report must allow for clarification/questions (speak back what you hear)

S

Situation

The problem you are communicating: _____

Current BP: _____ Pulse: _____ Resp: _____

O_2 Sat: _____ FSBS (if they have Diabetes): _____

Oxygen? _____ L/min via (✓): _____ Face mask _____ Nasal canula

Code status (✓): _____ Full _____ DNR

ACP? (✓): _____ MOST _____ MOLST _____ POST _____ POLST

On blood thinner? (✓): Yes _____ No _____ INR (Date and Level)_____

Allergies: _____

Hospice involved? _____

B

Background

Check all that apply (✓): _____ COPD _____ Dementia _____ Atrial Fib

_____ HF _____ CAD _____ MI _____ Stroke _____ Thyroid Dx _____ CKD

_____ Anemia _____ Cardiomyopathy _____ Antibiotics in the past two weeks

_____ Valvular Heart Disease _____ Obstructive Sleep Apnea

Most recent hospital discharge date: _____(mm)/ _____(dd)/ _____(yy)

Any other pertinent background information:

A Assessment (be prepared to discuss any changes in prior assessments)

Findings from the body system (✓):

Neuro	_____ Alert _____ Oriented (_____ x1 _____ x2 _____ x3) _____ Combative _____ Disoriented _____ Stuporous _____ Unresponsive
Head, Mouth	_____ Moist _____ Pink _____ Grooves in tongue _____ Dry oral mucosa
Lung	_____ Resp unlabored _____ labored _____ Using diaphragm Nail bed color: _____ _____ Rhonchi; Location: _____ _____ Crackles; Location: _____
Heart	Rhythm (✓): _____ Regular _____ Regularly irregular _____ Irregularly irregular _____ ICD _____ Jugular Vein Distention _____ Pacemaker
Gastrointestinal	_____ Soft _____ Firm _____ Distended _____ Tender Hepatojugular Reflux (✓): _____ Yes _____ No
Extremities	_____ Edema; Location: _____ Temperature (felt with the back of the hand) (✓): _____ Cool _____ Warm
Current Medication	_____ ACEI _____ ARB _____ Beta Blocker _____ Diuretic (dosage): _____
Most Recent Labs	_____ Last Creatinine _____ Potassium _____ INR _____ CBC _____ BNP

R Recommendations/Request

Order an analgesic? _____ (pain rating should match order)

Order medication for symptom MGMT? _____

Referral? (Chaplain, social working, PT/OT, etc.) _____

Contact the family? _____ Other: _____

Appendix D

LTC Resident Value Checklist Assessment

Values Checklist and Guide: My Choices Near the Ending of Life

1. Most important of all to me when thinking about end-of-life choices are:

_____ physical comfort
_____ family/friends present
_____ maintain my dignity & integrity
_____ relief of pain and suffering
_____ to die naturally at home, if possible
_____ live as long as possible no matter what
_____ other: _____

2. In terms of living through serious illness and the ending of life, I define quality of life as:

_____ reflecting my values & beliefs
_____ recognizing family & friends
_____ the ability to direct my life decisions
_____ making my own decisions
_____ having a say about care needs
_____ maintaining my sense of independence
_____ able to do things I enjoy doing
_____ receiving palliative (comfort) care & hospice
_____ other: _____

3. If I could choose where I would be when I am dying, I would want to be:

_____ at home _____ in the hospital _____ in the nursing home
_____ other: _____

4. What do you think about life-sustaining treatment? This means any medication, medical procedure or device that could be used to keep you alive when you otherwise would naturally die. This would include such things as: Cardiopulmonary resuscitation (CPR), using a breathing machine, using mechanical means to maintain blood pressure and heart rate, antibiotics, getting food or water by medical device (tube feeding), and other invasive treatments. What would you want to have in each situation below?

- If you could recover sufficiently to be comfortable and active? _____ use _____ don't use
- If you were near death with a terminal illness? _____ use _____ don't use
- If your brain's thinking function were destroyed? _____ use _____ don't use
- If you were moderately disabled by dementia e.g., Alzheimer's Disease?
  _____ use _____ don't use

5. What are some of the other things that are important to you?

_____ nature of care should not devastate my family
_____ my religious beliefs and traditions
_____ to be pain free and comfortable
_____ after death care issues
_____ my spiritual care and wellbeing
_____ to be in a comfortable peaceful setting
_____ to be returned to my homeland after I die, that being
_____ other: _____

6. Which family and friends would help you with your care when you are unable to care for yourself?

_____

7. Do your loved ones know your wishes, values and beliefs about end-of-life care?

_____ yes _____ no

8. Have you talked to your doctor about these issues?

_____ yes _____ no

If you are using this as part of your Advance Care Plan, please Print Name, Sign and Date below.

Print Name: _____ Sign: _____
Date: _____

Other Things to Consider Concerning My End of Life Wishes

(If you do not do this part now, it is a good idea to think about these things and complete later.)

9. I am a member of an organized church or religion? _____ yes _____ no

My specific faith, congregation or spiritual practice is _____
_____

10. To help attend to my spiritual needs as death approaches, I would call upon:
Name(s): _____ Relationship: _____ Phone: _____
_____

11. When I am dying I would like my surroundings as follows and I would like to have with me these special possessions:
_____
_____

12. As I am near to the end of my life, I would like these people informed:
_____
_____

13. Following my death, I would like to also inform these people:
_____
_____

14. I have written or will write an announcement of death (obituary): _____ yes _____ no

15. My wishes for after-death care are for _____ natural death care _____ burial
_____ cremation

My wishes for memorial activity are as follows:
_____
_____

16. If I have made arrangements, the contact person/phone is: _____

17. Other things important for someone to know about me, in the event that I become incapacitated, or my death is close at hand?

_____

_____

18.

_____ _____

(your signature/date) (optional - witness signature/date)

Please attach additional sheets if needed. When completed, copy, and share this with your doctor, family and caregivers and make time for meaningful conversations in the process. It also is important to properly complete an Advance Health Care Directive (AHCD) and distribute that to people who may need to guide your care if and when you become unable to make your wishes known and honored. When completing the AHCD, we recommend that you attach to your AHCD this completed Values Checklist and Guide (or something similar) and note in AHCD under "Special Instructions:" see Values Checklist attached. Advance Health Care Directive forms are available without charge from physicians, hospitals, social service providers, care homes and others. Permission is herein granted for you to reproduce this for individual personal use. Professionals must have permission to reproduce and use.

Appendix E

Holistic End-of-Life in LTC Facilities Knowledge Assessment Test

Purpose: The individual who will be managing use of this evidence-based assessment guideline and coordinating education of the staff should be the only one who has access to the test key. Following proper education with regard to Holistic End-of-Life Care in Long Term Care Facilities, each member of the nursing staff and/or physician/mid-level provider should be given an opportunity to take this test. Use this test as a learning tool only. Please have the nursing staff and/or health care providers take this test without the answer key present, and once they are done, let them code how many questions they answered correctly and incorrectly. Guidance in determining why they answered as they did can also be part of the learning process.

Knowledge Assessment Test Key

1. A
2. E
3. A
4. A
5. A
6. D
7. A
8. C
9. A
10. E

Holistic End-of-Life in LTC Facilities Knowledge Assessment Test

1. In general, the evidence confirms that significant gaps remain in ensuring LTC residents and their family members receive high-quality EOL care.
    A. True
    B. False

2. The interprofessional care team should consist of:
    A. The LTC resident
    B. Nurses
    C. CNA's
    D. Managing providers
    E. All of the above

3. Pain in cognitively impaired older adults can best be assessed utilizing which tool?
    A. PAINAD
    B. Numerical Rating Scale
    C. Brief Pain Assessment
    D. Critical-Care Observation Tool

4. The goal of the guideline is to ensure LTC residents are assessed and treated for spiritual wellbeing, mental wellbeing and symptomatic management, all aligning with their goals of care.
    A. True
    B. False

5. If a LTC resident is receiving opioid pain medications, they should have an order for a stool softener or laxative to prevent constipation.
    A. True
    B. False

6. Who may administer the FICA Spiritual History Tool?
    A. Nurses
    B. Managing providers
    C. Chaplains
    D. All of the above

7. The nurse assessing the LTC resident should utilize the SBAR form when communicating with the interprofessional care team
    A. True
    B. False

8. When should a resident be screened for physical symptoms such as pain, constipation, and dyspnea?
    A. Upon Admission to LTC Facility
    B. Routinely throughout the care process
    C. Both A and B
    D. Neither A nor B

9. The main difference between palliative and hospice care is the life expectancy of the resident.
    A. True
    B. False

10. If a question regarding a resident's medical wishes arises, one can access the chart and refer to this document for guidance:
    A. MOST Form
    B. MOLST Form
    C. POST Form
    D. POLST Form
    E. Any of the above

Total Score: _____

Appendix F

Holistic End-of-Life Care in LTC Facilities Process Evaluation Monitor

Introduction: The purpose of this monitor is to evaluate perceived understanding and support of each nurse, certified nursing assistant and health care provider in carrying out the *Holistic End-of-Life Care* guideline.

Instructions: PLEASE COPY THE FORM ON THE NEXT PAGE and ask each nurse, certified nursing assistant, and health care provider who use the guideline to complete it approximately one month following initial use of this assessment guideline.

Once the nursing/professional staff members that are using the assessment guideline complete the Process Evaluation Monitor, the individual in charge of implementing the guideline should provide feedback to each person who completed a form and offer further education or support as needed. For the 10 questions, please tally up the responses provided by adding up the numbers circled. For example, if Question 1 is answered '2' and Question 2 is answered '3' and Question 3 is '4' the nurse's score for those three questions (2+3+4) equal 9. The total score possible for this monitor is 40, while the lowest score is 10. Those who have the higher scores on this monitor are indicating that they are well equipped to implement the guideline and understand its use and purpose. On the other hand, those who have relatively low scores need more education and support in the use of the guideline.

Process Evaluation Monitor

Directions: Please circle the number that best communicates your perception about your use of the Holistic End-of-Life Care in Long Term Care Facilities guideline.

	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
1. I feel knowledgeable to carry out the EOL Care in LTC Facilities assessment guideline.				
2. Implementing the EOL Care in LTC Facilities guideline enhances the quality of nursing care in the facility				
3. I feel supported in my efforts to implement the EOL Care in LTC Facilities guideline.				
4. I feel well prepared to carry out the EOL Care in LTC Facilities guideline with the assistance of the facility management.				
5. I am able to identify symptoms of physical and psychosocial distress by using the EOL Care in LTC Facilities guideline.				
6. I am able to identify and carry out the essential activities of the EOL Care in LTC Facilities guideline.				
7. I had enough time to learn about the EOL Care in LTC Facilities guideline before it was implemented.				
8. We are managing residents EOL symptoms better with the use of the assessment guideline.				
9. The assessment guideline enables me to meet the health promotion needs for most palliative care residents.				
10. I feel included as part of the interprofessional team				

Total Score: _____

Appendix G

Holistic End-of-Life Care in LTC Facilities Outcome Monitor

Instructions: PLEASE MAKE A COPY OF THE FORM ON THE NEXT TWO PAGES and place it in the health record of each resident who is receiving the End-of-Life Care in Long Term Care Facilities guideline. The four outcomes on this form should be assessed and recorded for each resident on a monthly basis. For residents receiving the intervention, please keep a record of the changes observed in their health records.

Place the appropriate criteria key next to each separate outcome for each resident assessment. We have provided a total of 8 boxes, which represent the first eight intervals to be measured. (An outcome may be evaluated through multiple data sources, for example, an individual being managed using the Holistic End-of-Life Care in Long Term Care Facilities guideline may report a decrease in heart failure severity through resident interview, and the resident's health record may indicate no weight gain for the week.)

EXAMPLE

Directions: Please place the appropriate key next to the outcomes for each assessment period.

Criteria Key: **Y = Yes**/met criteria **N = No**/criteria not met **J = Justified Variation**

(**Justified Variation** e.g. patient not included in the monitor; note **why** patient is not included)

Criteria	Admission	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6
Outcome 1: Pain							
Resident Interview Reveals Lower Score Compared to Previous Assessment per PAINAD or NPRS	6/5/2020	N	Y	Y	Y	N	N

Outcome Monitor

Directions: Please place the appropriate key next to the outcomes for each assessment period.

Criteria Key: Y = **Yes**/met criteria N = **No**/criteria not met J = **Justified Variation**

(**Justified Variation** e.g. patient not included in the monitor; note **why** patient is not included)

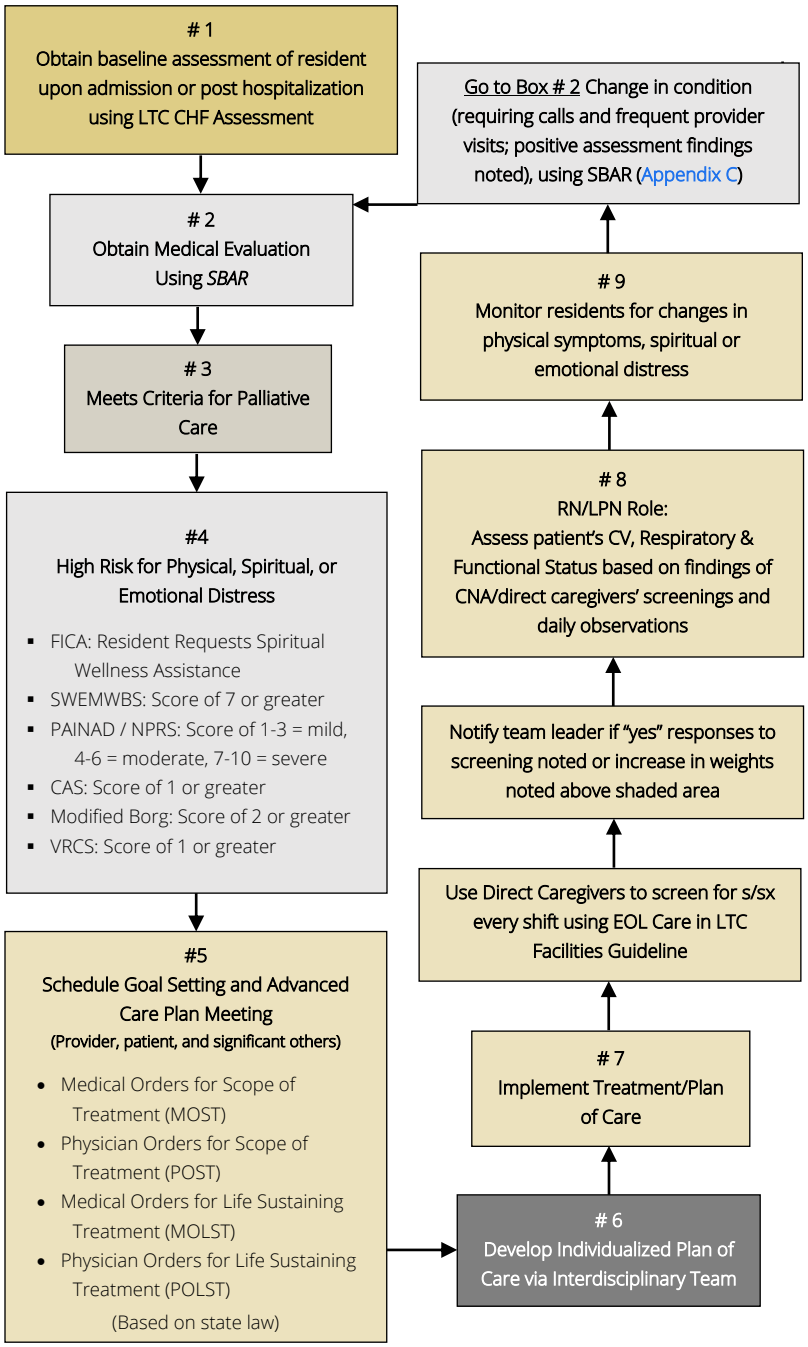
Outcomes	Admission	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Outcome 1: Pain							
Resident Interview Reveals Lower Score Compared to Previous Assessment per PAINAD or NPRS							
Resident Appears Physically Comfortable (No moaning, restlessness, guarding, facial expressions, tension)							
Resident Family Member States that the Resident Appears Comfortable							
Outcome 2: Dyspnea							
Resident Interview Reveals Lower Modified Borg Scale Score							
Resident Appears Comfortable and in no Distress (No use of accessory muscles, no nasal flaring, increased respiratory rate, tripod positioning)							
Resident Family Member States that the Resident Does not Appear Dyspneic							
Outcome 3: Constipation							
Resident Interview Reveals a Lower CAS Score Than Previous Assessment							
Last Documented BM Less Than 3 Days Ago							
Resident Family Member Reports no Evidence of Resident Constipation							

Outcomes	Admission	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Outcome 4: Congestion							
Resident Interview Reveals a Lower VRCS Score Than Previous Assessment							
Resident Family Member Reports no Evidence of Resident Congestion							
Outcome 5: Mental Wellbeing							
Resident Interview Reveals a Higher SWEMWBS Score Than Previous Assessment (Indicating positive mental wellbeing)							
If Responded "No" to Above, Have Appropriate Referrals Been Placed? (Social Work, Spiritual Advisor, Counseling)							
Resident Family Member Believes Resident is Emotionally Stable							
Outcome 6: Spiritual Wellbeing							
FICA Spiritual History Tool has been Completed and Documented							
If Appropriate, Referral has been Placed (Chaplain, Specific Spiritual Provider)							
Outcome 7: Goals of Care							
Resident has Documentation of MOST, MOLST, POST, or POLST Form in Care Chart							

Comments:

Appendix H

Non-Pharmacologic Approach to Holistic End-of-Life Care in LTC Facilities



REFERENCES

Alghadir, A.H., Anwer, S., Iqbal, A., & Iqbal, Z.A. (2018). Test-retest reliability, validity, and minimum detectable change of visual analog, numerical rating, and verbal rating scale for measurement of osteoarthritic knee pain. *Journal of Pain Research, 11*, 851-856. https://dx.doi.org/10.2147/JPR.S158847

BC Centre for Palliative Care. (2017). *B.C. inter-professional palliative symptom management guidelines. Retrieved* from https://bc-cpc.ca/publications/symptom-management-guidelines/symptom-management-guidelines-printable/

Borneman, T. (2018). Assessment of spirituality in older adults: FICA spiritual history tool. *Try This: Best Practice in Nursing Care for Hospitalized Older Adults.* https://hign.org/sites/default/files/2020-06/Try_This_SP_5.pdf

Carpenter, J.G., Lam, K., Ritter, A.Z., Ersek, M. (2020). A systematic review of nursing home palliative care interventions: Characteristics and outcomes. *Journal of the American Medical Directors Association 21*(5), 583-596. https://doi.org/10.1016/j.jamda.2019.11.015

Coyle, N. (2015). *Oxford textbook of palliative nursing.* In B.R. Ferrell, N. Coyle, & J. Paice (Eds.). Oxford University Press.

Dudgeon, D. (2015). Dyspnea, terminal secretions, and cough. In B.R. Ferrell, N. Coyle, & J.A. Paice (Eds.), *Oxford Textbook of Palliative Nursing* (217-236). Oxford University Press.

Economou, D.C. (2015). Bowel management: Constipation, diarrhea, obstruction, and ascites. In B.R. Ferrell, N. Coyle, & J.A. Paice (Eds.), *Oxford Textbook of Palliative Nursing* (217-236). Oxford University Press.

Fat, L.N., Scholes, S., Boniface, S., Mindell, J., & Stewart-Brown, S. (2016). Evaluating and establishing national norms for mental wellbeing using the short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS): Findings from the health survey for England. *Quality of Life Research 26,* 1129-1144. https://dx.doi.org/10.1007/s11136-016-1454-8

Fry, M., & Elliott, R. (2018). Pragmatic evaluation of an observational pain assessment scale in the emergency department: The pain assessment in advanced dementia (PAINAD) scale. *Elsevier*. https://doi.org/10.1016/j.auec.2018.09.001

Ferrell, B.R., Coyle, N., & Paice, J. (Eds.). *Oxford textbook of palliative nursing.* Oxford University Press, 4th Ed.

Gadlin, H. (2007). The ombudsman: What's in a name? *Negotiation Journal 16*(1), 37-48. https://www-proquest-com.echo.louisville.edu/docview/205148702?accountid=14665

Gonella, S., Basso, I., Marinis, M., Campagna, S., & Giulio, P. (2019). Good end-of-life in nursing home according to the family carers' perspective: A systematic review of qualitative findings. *Palliative Medicine 33*(6), 589-606.

Harrington, C. (2019). Assessing heart failure in long-term care facilities. (H.K. Butcher & R.M.M. Maas, Eds.). Series on Evidence-Based Practice Guideline, Iowa City, IA: The University of Iowa College of Barbara and Richard Csomay Center for Gerontological Excellence.

Institute of Medicine. (2015). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC:* The National Academic Press. https://doi.org/10.17226/18748

Kolb, H., Snowden, A., & Stevens, E. (2018). Systematic review and narrative summary: Treatments for a risk factors associated with respiratory tract secretions (death rattle) in the dying adult. *Journal of Advanced Nursing 74*, 1446-1462. https://doi.org/10.1111/jan.13557

Modified borg dyspnea scale. (n.d.). Lung Foundation Australia. Retrieved April 10, 2021, from https://pulmonaryrehab.com.au/~resources/02_Patient_assessment/04_modified_borg_dyspnoea_scale.pdf

Molin, A.D., McMillan, S.C., Zenerino, F., Rattone, V., Grubich, S., Guazzini, A., & Rasero, L. (2012). Validity and reliability of the Italian constipation assessment scale. *International Journal of Palliative Nursing 18*(7), 321-325.

National Institute on Aging (2021). What are palliative and hospice care? https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care

Pivodic, L., Smets, T., Van den Noortgate, N., Onwuteaka-Philipsen, B.D., Engels, Y., Szczerbinska, K., Finne-Soveri, H., Froggatt, K., Gambassi, G., Deliens, L., & Van den Block, L. (2018). Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study. *Palliative Medicine 32*(10), 1584-1595. https://doi.org/10.1177/0269216318800610

Puchalski, C. & Romer, A.L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine 3*(1), 129-137.

Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS). (2008). NHS Health Scotland, University of Warwick and University of Edinburgh. Retrieved April 10, 2021, from https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs

Temkin-Greener, H., Li, Q., Li, Y., Segelman, M., Mukamel, D.B. (2016). End-of-life in nursing homes: From care processes to quality. Journal of Palliative Medicine 19(12), 1304-1311.

Victoria Hospice Society. (2006). *Victoria Respiratory Congestion Scale (VRCS).* Medical care of the dying, 4th ed.

Warden, V., Hurley, A.C., & Volicer, L. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association 4*(1), 9-5.

Cullen, L., Hanrahan, K., Farrington, M., DeBerg, J., Tucker, S., & Kleiber, C. (2018). *Evidence-based practice in action: comprehensive strategies, tools, and tips from the University of Iowa hospitals and clinics*. Sigma Theta Tau.

Butcher, H. K., Bulechek, G. M., Dochterman, J. M., & Wagner, C. M. (Eds.). (2018). *Nursing interventions classification (NIC)* (7th ed.). St. Louis, MO: Elsevier.

Moorhead, S., Swanson, E., Johnson, M., & Maas, M., (Eds.). (2018). *Nursing outcomes classification (NOC): Measurement of Health Outcomes* (6th ed.). St. Louis, MO: Elsevier

CONTACT RESOURCES

If you have any questions regarding this assessment guideline, please contact the author:

In writing:
Andrew Aschbacher, BSN, RN
3705 Warner Ave
Louisville, Ky 40207
akasch01@louisville.edu

By Phone:
(502) 671 - 3459

Or you may contact the Csomay Center using the information below.

In Writing:
Barbara & Richard Csomay Center for
Gerontological Excellence
University of Iowa, College of Nursing
492 NB Iowa City, IA 52242

By Phone:
(319) 335-7084