Background
An increasing number of patients with progressive chronic illnesses receive care and ultimately die in long term care facilities. Most of these patients can benefit from palliative care in addition to any curative or restorative therapies they receive. For many individuals, curative or restorative therapies may be unreasonable goals, or goals of care that the patient or responsible party do not wish to pursue. Some patients with palliative needs also may benefit from hospice care.

For those patients who may benefit from palliative care or enrollment in a hospice program, AMDA believes that the attending physician and the medical director of the facility can make valuable contributions to the interdisciplinary team. Facilities benefit when attending physicians and facility, medical directors encourage development and implementation of policies, processes, and quality improvement activities that address palliative care and end-of-life care.

Collaborative care with a hospice organization may pose challenges for the nursing home medical director. Federal and state laws and regulations have served to increase the medical director’s administrative responsibilities and liabilities. When a hospice care team enters the facility to collaborate with facility’s staff and provide comprehensive palliative care, the facility medical director must deal with an added layer of complexity.

For the purposes of this paper, it is important to review some differences between palliative care and hospice care.

- **Palliative care** refers to those processes of care designed to prevent and treat physical, emotional and spiritual suffering in order to enhance quality of life for patients with chronic, progressive illnesses. Palliative care strives to improve the quality of life regardless of the stage of illness or types of treatment. Palliative care may be appropriate when a patient is receiving aggressive curative treatments or is in the final days and weeks of life.

- **Hospice care** refers to both a philosophy and a system of palliative care for patients who are considered terminal by virtue of an estimated life expectancy of six months or less. Hospice care addresses not only physical, emotional, and spiritual suffering, but provides support to families during the final months of life and in the bereavement period after death.

- The **Medicare Hospice Benefit**[^1] is an entitlement that funds hospice care for terminal Medicare beneficiaries. In long term care facilities, the care model, quality indicators, and regulatory oversight prioritize and reward restorative and rehabilitative care. The Omnibus Budget Reconciliation Act of 1987 (OBRA 87, also known as the Nursing Home Reform Act) states that a

[^1]: Hospices operate under Title 18 of the Code of Federal Regulations, whereas skilled nursing facilities operate under Title 19.
AMDA believes there are three key principles of care that should be observed for all patients in a facility, and especially for those receiving hospice care:

1. The nursing home medical director, as well as the attending physician, should stay involved in patient care;
2. The attending physician should continue as the primary care provider for his patient; and
3. The nursing home medical director should be in contact with the hospice medical director if any concerns or problems develop.

These three principles must guide the nursing home medical director when overseeing and coordinating the provision of quality palliative care, end-of-life care, and hospice care within the facility. The purpose of this document is to delineate the role and responsibilities of the medical director when care is delivered collaboratively by hospice and nursing home personnel. This document will also address the challenges and opportunities for quality improvement as facility personnel integrate appropriate principles and practices of palliative care into patients’ comprehensive plans of care.

QUALITY ASSURANCE/QUALITY IMPROVEMENT

The way people die is an important measure of the care provided in the long term care facility. Thus, the nursing facility medical director should include quality measures to assess, evaluate, and determine trends of palliative care, end-of-life care, and hospice care in their quality assurance and improvement process. This white paper includes examples of potential areas to be considered in a facility’s quality assurance and improvement process. Over a period of time, the data that are reported to the facility’s Quality Assurance (QA) Committee will help establish quality of care benchmarks for the facility.

Pain Management

Sometimes defined as the 5th vital sign, a patient’s pain may be measured by several different instruments. These instruments generally consist of a piece of paper on which a simple scale is marked, relating to the level of pain the patient is feeling. The higher the patient points are on a scale is an indication of how much pain the patient is feeling. A pain intensity scale marked from 0 to 10 is an effective method of quantifying a patient’s pain. In some instances, replacing the numerals 0 to 10 with graphic caricatures of faces in various stages of pain may also prove effective in assessing pain. For patients with dementia, or communication difficulties, other methods exist to quantify pain and discomfort. Other potentially useful measures of pain management include the length of time it takes to control pain symptoms, the utilization of the various pain medications, and the various routes used for the administration of the pain medication.

The QA Committee may choose to measure separately the management of different types of pain including chronic pain, acute pain, or pain found in actively dying patients. The QA Committee should monitor these data for all patients with pain, including those enrolled in hospice. For guidance on the management of pain, refer to the AMDA Clinical Practice Guideline Pain Management in the Long-Term Care Setting.

Non-pain Symptom Management

Non-pain symptom management should be monitored using instruments similar to those utilized for the assessment of pain. Some of the non-pain symptoms experienced by patients in long term care settings include dyspnea, anxiety, delirium, anorexia, fatigue, depression, constipation, diarrhea, nausea and
vomiting. As in pain management, the QA Committee could monitor these data for all patients with distressing non-pain symptoms including those enrolled in hospice.

**Palliative Care Quality Measurement**

The QA Committee may choose to monitor multiple elements of palliative care processes and outcome to identify areas for improvement and set benchmarks for quality. Elements of palliative care conducive to quality improvement might include control of pain and non-pain symptoms, timely advance care planning, site of end of life care, family support from facility staff, support provided to facility staff by hospice personnel, collaboration between the facility and the hospice provider. (See Appendix: Possible Measures of Quality Palliative Care in Long Term Care)

**Bereavement**

A patient’s death may be associated with grief for the family, staff, friends, and fellow patients. Facilities may consider periodic memorial services for those who have died, providing access to bereavement services for those in need, and providing grief counseling for staff. Facilities may choose to document bereavement services provided as an addendum to the deceased patient’s chart.

**Further Documentation**

Some state surveyors have requested documentation of the patient’s advance directives (if any), and of the proxy’s awareness of the patient’s advanced directives. It is important to document discussions with patients or their surrogates about such critical issues as Do Not Hospitalize orders, decision about artificial nutrition and hydration for unintentional weight loss, palliative versus curative care for pressure ulcers, and other decisions to forego or limit evaluations and interventions for conditions arising at the end of life. The hospice provider, nursing facility, and attending physician should have policies and practices in place to address these issues. This could be an assigned or shared responsibility between the hospice provider, nursing facility, and attending physician, but note that duplication of services in this may add to the burden and stress experienced by families. “Physician Orders for Life-Sustaining Treatment” (“POLST”) forms are one example of useful means of quickly conveying patient or proxy directions.
MEDICAL DIRECTORS
Nursing Facility and Hospice Medical Directors Relationship

The relationship of the nursing home medical director to the hospice program is worthy of mention. A good working relationship is likely to result in the greatest satisfaction for patients, families, and staff. The nursing home medical director and attending physician should stay involved in the patient’s care when a hospice agency is involved.

The nursing home medical director should be in contact with the hospice medical director about any concerns related to patient care or collaboration between the hospice and the facility. Attendance at the hospice interdisciplinary team meeting (IDT) might be appropriate, especially if there are issues to be addressed or discussed concerning the role and responsibilities of hospice personnel within the nursing facility. Conversely, attendance of facility care plan meetings by the hospice medical director and other involved hospice interdisciplinary staff is suggested to ensure complete coordination of care.

The nursing facility medical director may need to educate hospice personnel about certain nursing home regulations.

The attending physician should continue as the primary care provider for his patient. If the physician is not working for the hospice, they can bill Medicare for their service as usual. For instructions as to how to bill for hospice services, refer to the Medicare Claims Processing Manual, Chapter 11, accessible on the CMS website at http://www.cms.hhs.gov/manuals/downloads/clm104c11.pdf.

If the attending physician feels uncomfortable or unsure about the palliative care needed for the patient, such as appropriate symptom interventions, he/she can always consult with the hospice medical director.

The nursing facility medical director or attending physician should retain responsibility for oversight of the patient’s overall plan of care, contingent on the advice, counsel, and agreement of the hospice interdisciplinary team including the hospice medical director.

Ensuring proper coordination and collaboration when creating and implementing the patient’s care plan should be the joint responsibility of the nursing facility medical director or designee, the patient’s attending physician, and members of the facility’s interdisciplinary team.

AMDA recommends that the skilled nursing facility or nursing facility medical director designate members of the interdisciplinary group with advice and consent of the hospice medical director.

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2 That the regulatory relationship between the hospice medical director and the nursing facility medical director when hospice services are being provided in the nursing facility currently is being considered by Centers for Medicare & Medicaid Services. On May 27, 2005, CMS released CMS-3844-P, Medicare and Medicaid Programs: Hospice Conditions of Participation; Proposed Rule, affecting Federal Register §42 CFR Part 418. The Proposed Rule would grant authority of the patient’s interdisciplinary team’s leadership to the hospice medical director when services are being provided in the nursing facility. AMDA submitted comments requesting CMS to revise the proposed rule to grant authority of the interdisciplinary team’s leadership to the nursing facility medical director with the advice and consent of the hospice medical director. CMS expects to issue its Final Rule in 2007 or 2008.

3-5 This recommendation is contingent on the release of the Final Rule on Hospice Conditions.
**Education**
Both the nursing facility medical director and the hospice medical director have roles in providing education to the patient’s caregiving team.

1. The hospice medical director should promote knowledge and competence in palliative care for all members of the caregiving team including nursing assistants, nurses, and attending physicians as appropriate.

2. The facility medical director is encouraged to tailor education to the needs of the facility staff. Educational presentations related to palliative and hospice care might address these topics:
   a. Assessment and management of pain and distressing non-pain symptoms
   b. End-of-life decision making
   c. Medical ethics
   d. Hospice Medicare regulations
   e. Palliative care principles
   f. Bereavement
   g. Healthy coping skills for caregivers

3. The nursing facility medical director should offer expertise in long term care and clinical practice in the nursing home environment to hospice agencies.

**Marketing**
A hospice program can be represented to physicians, medical community, medical facilities, and the community through articles, presentations, or videos. Any gifts offered to physicians or nursing home staff members during marketing efforts should be of nominal value, seen as aids to providing good care, and not be contingent on receipt of referrals.

**Utilization Review and Quality Assurance**
The nursing facility medical director can exercise medical leadership in the facility’s Continuous Quality Improvement Program (CQI) by monitoring process and outcomes care described above. Many quality improvement efforts could be made a joint effort between the medical directors of both the nursing facility and the hospice.

**Administration**
The nursing facility medical director should use administrative authority to enhance palliative care and hospice-facility collaboration through the following actions:

1. Encouraging implementation of policies and procedures to recognize, assess, treat and monitor pain and distressing non-pain symptoms associated with chronic illness and the dying process.
2. Encouraging integration of emotional and spiritual elements into patients’ care plans.
3. Acting as liaison with the attending physician, consultants, and medical directors of hospitals, nursing homes, and managed care programs.
4. Being able to assume temporary responsibility for patient care on an emergency basis if the attending physician or designee is not available.
5. Using interdisciplinary meetings to review and monitor those elements of physician performance, care process and patient outcomes relevant to palliative and end-of-life care.

Clinical Duties
When appropriate, the nursing facility medical director may serve as a clinical resource in palliative care to the interdisciplinary team by participating in patient care rounds, home visits or family conferences.

SUMMARY
Hospices and nursing facility hospice programs must ensure that all of their residents receive high-quality palliative and end-of-life care, including pain and non-pain symptom management, informed decision making, advance care planning, emotional and spiritual support for patients and families, and bereavement support for caregivers and families. These are core domains of palliative and end-of-life care for older adults, and are essential to the mission both long term care facilities and hospice programs. This White Paper encourages long term care medical directors and attending physicians to be actively involved in the policies, procedures, and related activities that promote quality palliative care services.

The American Medical Directors Association offers more than 20 Clinical Practice Guidelines that may be used to aid the development of quality palliative care programs for residents in hospice programs, including *Pain Management in the Long-Term Care Setting*. Visit the AMDA website at [http://www.amda.com/info/catalog/](http://www.amda.com/info/catalog/) for a complete list of these resources.
Appendix: Possible Measures of Quality Palliative Care in Long Term Care

The following are examples of quality measures within the domains of palliative and hospice care:

Control of pain and non-pain symptoms
Goal: assessment and control of pain and non-pain symptoms.
Measures:
- Percentage of those assessed for pain or other distressing symptoms whose symptoms were controlled in the one-month, one-week, and 48-hour time periods prior to death.
- Percentage of families reporting good control of pain, dyspnea, agitation and other distressing symptoms in the last month, week and 48 hours of life.

Advance care planning
Goal: Timely discussions with patients and families about advance care planning documents like durable power of attorney for health care, living wills, and do not resuscitate orders
Measures:
- Percentage of advance care planning discussions recorded within 60 days of admission.
- Percentage of advance care plans that specify goals of care beyond DNR.
- Percentage of patients with documentation of discussion of diagnoses, prognosis, and goals of care.
- Percentage of families reporting that advance care plans and end-of-life wishes were honored.

Site of end of life care
Goal: To provide end-of-life care within the facility when possible.
Measures:
- Percentage of deaths occurring in the facility.
- Percentage of deaths that were anticipated and had a palliative care plan.

Family support from facility staff
Goal: to provide emotional, spiritual and bereavement support to families of patients with palliative care needs and those in the last months of life.
Measures:
- Percentage of residents or families who report an assessment of their emotional and spiritual needs.
- Family satisfaction with emotional and spiritual support provided.
- Percentage of families offered bereavement care.
- Percentage of families satisfied with bereavement care.
- Percentage of charts with documentation of bereavement needs assessment and care provided.
- Percentage of families who report respectful, clear and timely communication with physician, nurses and other caregivers about the dying resident.

Utilization of and satisfaction with hospice and palliative care programs
Goal: To provide timely access to palliative care and hospice consultation that improves quality of life for patients
Measures:
• Percentage of residents or families reporting being offered a hospice or palliative care referral.
• Family satisfaction with the care the patient received from the hospice team.
• Family satisfaction with emotional, spiritual and bereavement support for the family.

Collaboration between the facility and the hospice program
Goal: To assure optimum communication and cooperation between facility staff and hospice staff
Measures:
• Percentage of facility caregiving staff reporting being asked for input to the hospice care plan.
• Percentage of facility staff reporting that they maintained meaningful roles in the care provided to the patient.
• Percentage of facility staff reporting timely educational support from hospice staff.
• Percentage of facility staff reporting timely and effective assessment of the patient when needed.
• Percentage of facility staff reporting clear and timely communication of the hospice care plan.

FISCAL NOTE: None

RESOLUTION RESULTS: Passed. Becomes AMDA policy.