



Testimony on MDS 3.0

National Hospice & Palliative Care Organization

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The National Hospice & Palliative Care Organization (NHPCO) is a nonprofit membership organization representing hospice and palliative care programs. The organization is committed to improving end-of-life care and expanding access to hospice, thereby enhancing quality of life for dying Americans and their loved ones. In 2001, NHPCO estimates that 775,000 patients were served by approximately 3,200 hospices.

We are here to testify on the Minimum Data Set (MDS) because it has a tremendous impact on the care being delivered to terminally ill residents of nursing facilities, with or without hospice care. It has been statistically predicted that by 2020, 40% of Americans will die in a nursing facility and some states are currently approaching that percentage.

Research studies have been conducted to determine whether it is beneficial for a nursing facility and hospice to work together. The U.S. Department of Health and Human Services (DHHS) requested and supported a study that was published in 2000 and referred to as the “ASPE study”. The findings were validated by a subsequent study conducted by Brown University and support the role of hospice in the nursing facility. The study concluded that:

- Nursing home residents enrolled in hospice are clinically quite similar to non-hospice dying nursing home residents;
- Hospice residents are less likely to be hospitalized in the last 30 days of life (12.5% vs. 41.3%) and the last 90 days (24.5% vs. 53%);
- Hospice patients received superior pain assessments compared to those who did not receive hospice;
- Hospice patients had lower percentages for use of physical restraints, parenteral/intravenous feedings, or feeding tubes in place; and
- When hospice is working in a nursing facility, there is a beneficial “spillover” effect to non-hospice residents.¹

Despite the benefits of partnering in care, forming the relationships has been challenging for both providers. The survey and enforcement guidelines focus surveyors for both providers on the coordinated plan of care.

The Nursing Facility Conditions of Participation are applicable to all of the residents in a facility. Hospice patients are not exempt from these regulations. This includes the requirement that each resident is assessed using the MDS and follow the Resident Assessment Protocols (RAPs) in the care planning process. Hospice residents are included in the calculations of the quality indicators, although deterioration is an expected outcome in the dying process.

When a resident elects the Medicare/Medicaid Hospice Benefit the resident signs a consent form stating that they desire to receive palliative rather than curative care. The Hospice also has a written certification of terminal illness from the physician stating that the resident’s anticipated prognosis is six months or less if the illness runs its normal course. Even with this explicit documentation on the resident’s record, it is extremely difficult to accomplish the task of developing a palliative care plan. It is extremely difficult for facility staff to deviate from

¹Assistant Secretary for Planning and Evaluation (ASPE). U.S. Department of Health and Human Services. Synthesis and Analysis of Medicare's Hospice Benefit. March 2000.

curative, rehabilitative, and maintenance outcomes in fear that as the resident's condition deteriorates, their interventions will be misconstrued as substandard care.

Outcomes in palliative care are different. Palliative outcomes developed and supported by NHPCO are:

- **Self-Determined Life Closure**
Anticipating death, mentally competent residents will have full autonomy to make decisions about how the remainder of their life is spent within the allowances of law.
- **Safe and Comfortable Dying**
The resident will die free of distressing symptoms in an environment that does not aggravate or hasten dying.
- **Effective Grieving**
The expression of grief eventually supports the individual's ability to adjust to their environment without the deceased and regain the ability to invest in other activities and relationships. Grief work is relevant for the patient and other significant relationships that are lost.

These outcomes apply across settings including personal homes, hospitals, and long-term care facilities.

In order to overcome the barriers to providing palliative care in the Resident Assessment Instrument, NHPCO is proposing that a skip pattern for palliative care be included in the MDS 3.0. A draft proposal has been attached to my testimony for your review. Answers to these questions would initiate a note on the RAP summary sheet to instruct the assessor to develop a palliative care approach to the triggered problems. Resident Assessment protocols would provide interventions that would be appropriate for palliative care as exemplified in the new protocol for pain and the revised protocols for mood and delirium. Subsequently, the quality indicators would be adjusted to factor out those residents in which deterioration is anticipated as a resident approaches death. This would eliminate the negative impact of providing palliative care.

In closing, NHPCO encourages that these problematic areas be addressed in the MDS 3.0. In support of this endeavor, if the decision is made to include a palliative skip pattern, we would be willing to convene a group of experts in the field to continue work in developing and refining the questions for this section.

We appreciate the opportunity to testify and commend the effort to improve the effectiveness of the MDS.

DRAFT Palliative Care Skip Pattern

Section Z. New Evaluation for Palliative/End-of-Life/Hospice Care

Item Source			
	Z1.	Palliative Assessment	<p>Determining whether palliative care may be appropriate for the resident:</p> <p>a. Is the resident experiencing an irreversible decline or a decline unresponsive to treatment? 0. No 1. Yes</p> <p>b. Does the resident have advance directives indicating that he/she does not desire life-prolonging measures? 0. No 1. Yes</p> <p>c. Has the resident/responsible decision-maker indicated a desire for comfort, rather than curative care? 0. No 2. Yes</p> <p>d. Has the resident been diagnosed with a terminal or life-limiting illness? 0. No 2. Yes</p> <p>e. Would assessors be surprised if the resident died within the next 6 months? 0. No 1. Yes</p> <p>If any of questions a – d above are answered with Yes, or if question e is answered with No, proceed to Z2. Otherwise, skip the remainder of Section Z.</p>

	Z2.	Advance Directives	<p>(Check all that apply and document discussions with resident/decision-maker/physician)</p> <ul style="list-style-type: none"> a. Directive to Physician/Living Will b. Durable Power of Attorney for Health Care Decisions c. Do not Resuscitate c. Do not hospitalize d. Feeding restrictions e. Intravenous restrictions f. Other treatment restrictions 	
	Z3.	Decision Making Capacity	<p>Is resident capable of making treatment decisions? 0. No 2. Yes</p> <p>If no, who is responsible for making treatment decisions:</p> <ul style="list-style-type: none"> a. Power of Attorney for Healthcare b. Guardian c. Designated individual by State Law d. Other <p>Does the resident/family desire further information regarding treatment options? 0. No 2. Yes</p> <p>Is there conflict between resident/family members over treatment decisions? 0. No 2. Yes</p>	
	Z4.	Support Services	<p>Does the resident/family desire: (check all that apply)</p> <ul style="list-style-type: none"> a. Psycho-social support b. Religious/spiritual support c. Bereavement Support d. Hospice Care e. Guidance in executing a will f. Selecting a funeral home g. Making funeral arrangements h. Guidance in Executing Advance Directives 	

