REPORT 1 OF THE COUNCIL ON MEDICAL SERVICE (NOV-21)
End-of-Life Care
(Resolution 101-Nov-20)
(Reference Committee A)

## EXECUTIVE SUMMARY

Referred Resolution 101-Nov-20, "End of Life Care Payment," raised concerns regarding patients who may benefit from custodial nursing care at the end of their lives but are prohibited under current Medicare rules from electing skilled nursing facility (SNF) and hospice benefits at the same time for the same condition. Except under very limited circumstances, Medicare's hospice benefit does not pay for room and board for its enrollees in nursing, skilled nursing, or assisted living facilities. People who pay out of pocket for stays at these facilities may elect hospice if qualified, and if there is an agreement between the facility and a hospice. However, patients using Medicare's SNF benefit post-hospitalization typically cannot elect hospice under current program rules. Research has suggested that of the large numbers of Medicare patients enrolled in the SNF benefit at the end of their lives, many would have elected hospice if they had not needed room and board coverage.

In line with polls showing that most people would prefer to die at home, most Medicare hospice services are provided at patients' residences. The Council recognizes that there is an ongoing need for supportive care and assistance with activities of daily living services among many end-of-life patients and the importance of discharging these patients to appropriate settings—preferably where the patient resides—with necessary, affordable supports. The Council believes that hospice is well-suited to provide supportive care services as part of routine home care, as needed (since it already does so), and that the provision of such services as determined by patient need may improve quality of life and prevent utilization of higher intensity care. Accordingly, the Council recommends supporting Medicare coverage of and payment for supportive care services, including assistance with activities of daily living, as needed, under the hospice benefit.

The Council believes the costs and benefits of care models incorporating elements of SNF and hospice are worthy of further study and recommends support for study and pilot testing by the Centers for Medicare & Medicaid Services of care models that allow concurrent use of Medicare's hospice and SNF benefits. Because the Council expects that many Medicare patients will continue to be discharged to SNFs in the last months of life, it also recommends supporting increased access to palliative care services in that setting.

REPORT OF THE COUNCIL ON MEDICAL SERVICE

CMS Report 1-N-21

Subject: End-of-Life Care
(Resolution 101-Nov-20)

Presented by: Asa C. Lockhart, MD, MBA, Chair

Referred to: Reference Committee A

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At the November 2020 Special Meeting, the House of Delegates referred Resolution 101, "End of Life Care Payment," which was sponsored by the New York Delegation. Resolution 101-Nov-20 directed the American Medical Association (AMA) to petition the Centers for Medicare & Medicaid Services (CMS) to allow hospice patients to cover the cost of housing (room and board) as a patient in a nursing home or assisted living facility, and to advocate that patients be allowed to use their skilled nursing home benefit while receiving hospice services. The Board of Trustees assigned this item to the Council on Medical Service for a report back to the House of Delegates. This report provides overviews of Medicare's hospice and skilled nursing benefits, differentiates between hospice and palliative care, summarizes AMA policy and makes policy recommendations.

BACKGROUND

Except under very limited circumstances, Medicare's hospice benefit does not pay for room and board for its enrollees including those in nursing, skilled nursing, or assisted living facilities, where many Medicare enrollees spend the end of their lives. People who pay out of pocket for stays at these facilities may elect hospice if qualified, and if there is an agreement between the facility and a hospice.[1] Medicaid pays for room and board for its dually eligible enrollees who qualify for hospice if the facility has an agreement with a hospice. However, patients using Medicare's skilled nursing facility (SNF) benefit post-hospitalization typically cannot elect hospice under current program rules. An exception would be for patients enrolled in hospice who need skilled care for a condition unrelated to their terminal illness. For example, if a cancer patient in hospice falls and breaks a hip, Medicare may pay for care in a SNF that the patient needs to recover from the hip injury.[2]

Post-acute care services, including skilled nursing and rehabilitation, are commonly used by Medicare patients in the last months of life. Nearly one quarter of hospitalized Medicare patients are discharged from a hospital to a facility, usually a SNF, for post-acute care.[3] Because Medicare typically does not pay for concurrent coverage of hospice services and SNF care, some patients who could benefit from hospice instead elect Medicare's SNF benefit so that their room and board costs are paid for. It is a common challenge at hospital discharge to find post-acute placements for seriously ill patients who may have limited life expectancies, require more care and assistance than can be provided at home, and cannot afford the costs of nursing care or stays at a long-term care facility out of pocket. Because Medicare covers room and board under the SNF benefit, this can become the preferred option for patients deemed eligible for the benefit, even though SNFs are designed to provide rehabilitative, not palliative, care and some SNF services may not be consistent with appropriate end-of-life care.

A frequently cited study from 2012 found that one-third of Medicare patients received SNF care during the last six months of life and nine percent died in a SNF, many within 30 days of admission.[4] More recent Centers for Disease Control and Prevention data reveal that, in 2016, nearly 30 percent of decedents 65 and over died at home, 28 percent died in the hospital, another 25 percent died in a facility that provides patient care (e.g., a nursing home, SNF, or long-term care facility), and 8.5 percent died in a hospice facility.[5] Research has suggested that of the large numbers of patients enrolled in the SNF benefit at the end of their lives, many would have elected hospice if they had not needed room and board coverage.[6] A 2018 *Health Affairs* blog describes this conundrum as follows:

> Either you get to receive restorative care in a nursing facility or end-of-life care at home. Unfortunately, this approach fails to meet the needs of real-world patients and families. If our current model persists, we will continue to cause patients and families to fall into a gap at some of the most tender moments in their family life cycle.[7]

Patients at the end of life who are too sick to benefit from skilled care, but are unable to return home, often remain hospitalized until death because there is no appropriate, affordable community placement available. Patients who need around-the-clock nursing care often end up in nursing facilities, including SNFs. Some Medicare enrollees cycle between hospital stays and nursing facilities in the last months of life, even when rehabilitation is unlikely to be successful. Many end-of-life patients remain at home with family members who become responsible for providing the care they need, including assistance with activities of daily living (ADL) services.

*Medicare's Skilled Nursing Facility Benefit*

Covered SNF services include post-hospital extended care services for which benefits are provided under Medicare Part A and include nursing care; bed and board in connection with furnishing of such nursing care; physical or occupational therapy and/or speech-language pathology services; medical social services; drugs, biologicals, supplies, appliances, and equipment; and other services necessary to the health of the patients.[8] Medicare does not cover SNF services for patients who only need custodial services (e.g., assistance with ADL such as bathing and dressing) but not skilled nursing benefits.

Medicare will cover skilled nursing under the SNF benefit if patients have a qualifying three-day hospital stay and documented daily skilled care needs, although CMS waived SNF three-day stay and discharge requirements during the public health emergency so that hospitals could focus on COVID-19 care. Care in a SNF is generally covered if it is documented that the patient requires daily skilled services that must be performed by or under the supervision of a professional and can only be provided to an inpatient at a SNF. Services must be reasonable and necessary for the treatment of a patient's illness or injury and consistent with the individual's medical needs and medical practice standards. According to the Medicare benefits manual, coverage does not depend on the patient's potential for improvement from the nursing care and/or therapy, but rather on the patient's need for skilled care.[9] Nonetheless, patients need to be able to participate in daily therapy services to be eligible for the SNF benefit and some seriously ill patients receiving hospice care cannot do so.

Medicare will cover up to 100 days of SNF care but only pays 100 percent of the costs for the first 20 days. At day 21, patients must begin paying a copay ($185.50 per day in 2021) through day 100 of a covered stay.[10] SNF services are costly; in 2019, Medicare's median payment per day was $498 and its median payment per stay was $18,559. Medicare spending on SNF services in 2019—when almost 1.5 million Medicare patients used the SNF benefit—was $27.8 billion.[11] In addition

to providing post-acute care, most SNFs are also certified to provide long-term care (nursing home care) that is not covered by Medicare.

*Medicare's Hospice Benefit*

More than 1.6 million Medicare patients received hospice services in 2019 at a total cost of $20.9 billion.[12] Medicare spending on hospice has increased substantially in recent years and was $15.1 billion in 2014, a figure cited by the Council in its most recent report on the program (Council on Medical Service Report 4-I-16, Concurrent Hospice and Curative Care). The literature on hospice costs to the Medicare program has been mixed, with some studies showing cost savings among hospice patients who are in the last one or two months of life. A MedPAC-commissioned analysis suggests that hospice produces savings for some patients, including cancer patients, but has not decreased net Medicare spending.[13]

The hospice benefit was introduced to the Medicare program in 1983 to provide a range of palliative and support services provided primarily in the home. To be eligible to elect hospice care under Medicare, patients must be certified as having a life expectancy of six months or less if the terminal illness runs its normal course; patients can be recertified for additional periods if they remain terminal.[14] Room and board costs in a nursing facility are not covered unless the patient qualifies for a short inpatient hospice or a respite stay. Covered hospice services include nursing care, medical social services, physician services, counseling and bereavement services, medical equipment and supplies (including prescription drugs), and other services included in a patient's individualized care plan. Skilled therapy services, such as physical, speech and occupational therapy are covered if they are deemed reasonable and necessary to manage symptoms or help maintain patient functioning. Under the supervision of a hospice nurse, hospice aides may provide personal care and some homemaker services that are deemed necessary to maintain a safe and sanitary environment in areas of the home used by the patient.[15]

Medicare pays for hospice care using per diem payment categories encompassing four levels of care: (1) routine home care, for which Medicare pays $199 per day for the first 60 days and $157 per day thereafter; (2) general inpatient care, paid $1,046 per day; (3) continuous home care, paid at a rate of $60 per hour; and (4) inpatient respite care, for which Medicare pays $461 per day (payment rates are for fiscal year 2021).[16] General inpatient care is provided around the clock in an inpatient facility (e.g., a hospice inpatient unit or SNF), usually for pain or symptom control which cannot be managed in other settings. It is intended to be short-term and, once symptoms stabilize, patients may be returned to their residences. Continuous home care consists mainly of nursing care provided on a continuous basis; this level of care is available only during brief periods of crisis and as needed to maintain the patient at home.[17] Inpatient respite care is provided in an approved facility on a short-term basis for respite. Service intensity add-on payments are made when hospice provides direct patient care by a registered nurse or social worker during patients' last seven days of life.

When Congress established Medicare's hospice benefit, it established two caps on payments to hospices—known as the inpatient cap and the aggregate cap—to ensure that hospice costs do not exceed the costs of conventional care. The inpatient cap limits the share of general and respite inpatient days that a hospice can provide to 20 percent of its total patient care days. Although this cap is rarely exceeded, the aggregate cap, which limits total aggregate payments any individual hospice can receive in a year ($30,684 in 2021), is exceeded by an estimated 16 percent of all hospices.[18]

Hospice use among Medicare enrollees has been incrementally increasing in recent years, such that 51.6 percent of enrollees who died in 2019 had used hospice services, up from 25 percent in 2000.[19] In 2018, a majority of hospice care days were provided at private residences, followed by assisted living facilities and nursing facilities, including SNFs.[20] Most care provided by hospice is routine home care, which accounted for 98 percent of Medicare-covered hospice days in 2019[21] and is in line with polls showing that seven in ten people would prefer to die at home.[22] Hospices vary and, even within the routine home level of care, the frequency and type of hospice visits and type and intensity of services may differ by patient and across hospices. While more people are turning to hospice at the end of life, families and the caregivers they hire provide much of the care and assistance with ADL services that home hospice patients often require.

*Palliative Care*

Palliative medicine focuses on reducing suffering, improving a patient's quality of life, and supporting patients with serious illness and their families. Palliative care can be provided alongside other medical treatments regardless of whether the patient can be cured and can be initiated early in one's disease course. Hospice is a type of palliative care for people who likely have six or fewer months to live and are willing to forego curative treatments for their terminal illness. Not all palliative care is hospice, although hospice care is always palliative.

The philosophies underlying hospice and palliative care are similar; however, care location, timing and eligibility often differ. At its core, palliative care is designed to assess, prevent and manage physical and psychological symptoms, address spiritual concerns, and focus on communications that establish patient goals of care and assist patients with medical decision-making about treatment options. Whereas hospice care is most commonly provided to patients in their homes, long-term care facilities, or wherever patients reside, non-hospice palliative care is frequently provided in hospitals or community settings such as cancer centers, clinics and nursing homes. Patients can receive palliative care while continuing curative treatment at any stage of their illnesses, and many studies have shown that early palliative care interventions improve quality of life and increase patient and family satisfaction. As suggested by Policy H-85.951, it is important for physicians to be familiar with hospice and palliative care resources and their benefit structures, as well as clinical practice guidelines developed by national medical specialty societies, and to refer seriously ill patients accordingly.

*Medicare Advantage Plans and Hospice*

Traditional Medicare has historically covered services related to a terminal illness under the hospice benefit even for patients enrolled in Medicare Advantage (MA) plans, meaning that fee-for-service Medicare has generally been responsible for coverage of most services while the MA plan is responsible for certain supplemental benefits. In 2021, CMS began testing the inclusion of hospice within the MA benefits package through the hospice component of the Value-Based Insurance Design (VBID) Model.[23] MA plans participating in the demonstration are permitted to offer palliative care as well as supplemental benefits such as meals, transportation, and in-home supports. The demonstration has started small; for example, Humana is offering the hospice benefit to enrollees in a handful of metropolitan areas. Humana's benefit allows transitional concurrent care and offers in-home respite care.[24]

*Disparities in End-of-Life Care*

Despite increases in the use of both hospice and palliative services in this country, racial disparities in end-of-life care persist, and communities of color remain underserved. Black and Latino people

are more likely to die in a hospital and be treated more intensively at the end of life than Whites.[25] Black Americans are less likely to utilize hospice than Whites and have more emergency department visits and hospitalizations in the last six months of life.[26] While some have posited that differences in trust of health systems and patient preferences contribute to existing disparities,[27] more research and efforts to understand and reduce these disparities, and address cultural competence in end-of-life care, are needed.

RELEVANT AMA POLICY

The AMA has long supported the goals of hospice and palliative care. Policy H-70.915 supports improved payments for health care practices caring for dying patients and encourages research into the needs of dying patients and how they could be better served by the health care system. Policy H-85.951, which was established through Council Report 4-I-16, (1) supports continued study and pilot testing by CMS of a variety of models for providing and paying for concurrent hospice, palliative and curative care; (2) encourages CMS to identify ways to optimize patient access to palliative care, and to provide appropriate coverage and payment for these services; and (3) encourages physicians to be familiar with local hospice and palliative care resources and their benefit structures and to refer seriously ill patients accordingly.

Policy H-85.966 maintains that the use of hospice should provide the patient and family with appropriate support, but not preclude or prevent the use of appropriate palliative therapies to continue to treat the underlying disease. Policy H-85.955 approves of the physician-directed hospice concept to enable the terminally ill to die in a more homelike environment; supports changes to the Medicaid program to allow provision of concurrent life-prolonging and palliative care; and supports broadening eligibility beyond six-month prognoses under Medicaid and Medicare hospice benefits. Policy D-155.995 supports greater evaluation of the use of disease management, case management, pay-for-performance, and end-of-life care programs for high-cost patients.

The AMA also has substantial policy on long-term care (LTC), including the financing of long-term services and supports (Policy H-280.945). Policy H-280.991 states that programs to finance LTC should cover needed services in a timely, coordinated manner in the least restrictive setting appropriate to the health care needs of the individual, and coordinate benefits across different LTC financing programs. Policy H-210.994 similarly supports the provision of LTC services in the least restrictive setting by affirming support of home health care as an alternative to nursing home or institutional care.

Policy H-290.982 supports: increasing public and private investments in home and community-based care, such as adult day care, assisted living facilities, congregate living facilities, and respite care; allowing states to use long-term care eligibility criteria that distinguish between persons who can be served in a home or community-based setting and those who can only be served safely and cost-effectively in a nursing facility; buy-ins for home and community-based care for persons with incomes and assets above Medicaid eligibility limits; and providing grants to states to develop new LTC infrastructures and to encourage expansion of LTC financing to middle-income families who need assistance.

Policy D-280.985 directs the AMA to work to identify additional mechanisms by which patients' out-of-pocket costs for SNF care can be fairly covered. Under Policy H-280.947, the AMA continues to advocate for elimination of the three-day stay rule and requirements related to inpatient hospitalization as a prerequisite before Medicare patients are eligible for SNF or LTC placement.

DISCUSSION

The 2015 Institute of Medicine (IOM) report, *Dying in America*, found that "significant problems remain in providing end-of-life care for Americans that is high quality and compassionate and preserves their choice while being affordable and sustainable."[28] The IOM report further highlighted the need for policy changes to support high-quality end-of-life care by stating:

> A major reorientation and restructuring of Medicare, Medicaid, and other health care delivery programs is needed to craft a system of care designed to ensure quality and address the central needs of all people nearing the end of life and their families. Current financial incentives and a lack of more appropriate alternatives drive a reliance on the riskiest and most costly care settings. These incentives should be changed, and positive alternatives should be further developed.
>
> In addition, many of the most urgent needs of these patients and their families are not medical per se and require the design and implementation of affordable support service programs that rigorously target the highest-risk patients and families, and tailor services to specific family needs as they evolve over time.[29]

The sentiment of the IOM report is relevant to the concerns raised by referred Resolution 101-Nov-20 regarding end-of-life care, for patients who may benefit from custodial nursing care but are prohibited under current rules from electing Medicare's SNF and hospice benefits at the same time for the same condition. The Council's work on long-term services and supports and home and community-based services has highlighted the challenges of caring for our aging population and identifying affordable and politically viable solutions that meet the care needs of many seniors. Council on Medical Service Report 4, which is also being considered at this meeting, recommends new AMA policy on the hospital at home model, which we believe could benefit some patients at the end of life.

Medicare's hospice benefit helps large numbers of patients and families, but it does not cover room and board for more than a small number of enrollees who qualify for short-term inpatient hospice, or a brief respite stay. Continuous home care that includes nursing and supportive care in one's residence is allowable under Medicare's hospice benefit but only during brief periods of crisis. Although routine home care makes up 98 percent of Medicare-covered hospice days, it is critical that general inpatient care, continuous home care, and respite inpatient care are available to hospice patients as their conditions change and their needs evolve.

The Council recognizes the ongoing need for custodial or continuous care, and ADL services, among many end-of-life patients and the importance of discharging these patients to appropriate settings—preferably where the patient resides—with necessary, affordable supports. The Council believes that hospice is well-suited to provide supportive care services as part of routine home care, as needed (since it already does so), and that the provision of such services as determined by patient need may improve quality of life and prevent utilization of higher intensity care. Accordingly, the Council recommends supporting Medicare coverage of and payment for supportive care services, including assistance with activities of daily living, as needed, under the hospice benefit.

The Council recognizes that a new room and board coverage benefit for hospice enrollees could significantly add to the costs of Medicare, a program already making headlines for its trust fund sustainability issues. The Council further recognizes that Medicare's SNF and hospice benefits were not designed to work in tandem and differ in many respects, including their mission and

goals, eligibility criteria, and duration of allowable services. SNFs are intended to provide rehabilitative—not palliative—services, some of which may not be needed at the end of life. Despite these differences, some similar services are provided by both SNFs and hospices, including skilled nursing, nursing aides, equipment, supplies and prescription drugs. A concurrent model would need to be carefully designed to prevent duplication of services, ensure administrative coordination and proper payment, and address site-neutral care. Although the Council does not recommend concurrent hospice and SNF care under the Medicare program, we believe the costs and benefits of care models incorporating elements of SNF and hospice are worthy of further study, especially given that COVID-19 may have impacted location preferences of hospice services. Accordingly, the Council recommends support for study and pilot testing by CMS of care models that allow concurrent use of Medicare's hospice and SNF benefits.

Because of financial incentives and coverage gaps within Medicare, the Council expects that many patients will continue to be discharged to SNFs in the last months of life, and some will die there, especially as the elderly population grows and the SNF benefit continues to be utilized for its room and board coverage. Consistent with AMA policy supportive of coverage and payment for palliative care, the Council recommends supporting increased access to palliative care services by Medicare patients in SNF. Finally, the Council acknowledges the breadth of existing AMA policy on hospice, palliative, and end-of-life care, and recommends reaffirmation of Policies H-85.966 and H-70.915.

RECOMMENDATIONS

The Council on Medical Service recommends that the following be adopted in lieu of Resolution 101-Nov-20, and that the remainder of the report be filed:

1. That our American Medical Association (AMA) support Medicare coverage of and appropriate payment for supportive care services, including assistance with activities of daily living, as needed, under Medicare's hospice benefit. (New HOD Policy)

2. That our AMA support study and pilot testing by the Centers for Medicare & Medicaid Services of care models that allow concurrent use of Medicare's hospice and skilled nursing facility (SNF) benefits for the same condition. (New HOD Policy)

3. That our AMA support increased access to comprehensive interdisciplinary palliative care services by Medicare patients in skilled nursing facilities. (New HOD Policy)

4. That our AMA reaffirm Policy H-85.966, which maintains that hospice care should provide the patient and family with appropriate physical and emotional support, but not preclude the use of appropriate palliative therapies to continue to treat underlying disease. (Reaffirm HOD Policy)

5. That our AMA reaffirm Policy H-70.915, which recognizes the importance of palliative care, encourages the education of health professionals and the public in caring for dying patients, and supports improved payment for health care practices that are important to good care of the dying patient. (Reaffirm HOD Policy)

Fiscal Note: Less than $500.

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