

# Advocacy for Vulnerable Patients: How Grassroots Organizations Can Influence Health Care Policy

Using case studies to make the case for home health reimbursement.

**N**urses and other home health care providers who work for visiting nurse organizations see patient vulnerability firsthand, as few members of the public ever do. Limitations in long-standing health care cost reimbursement policy have created a distinct kind of vulnerable patient, whose complex medical needs and social circumstances impose challenges in accessing adequate care.

As provisions of the Affordable Care Act (ACA) continue to be implemented, the United States will undergo the most comprehensive transformation of care delivery and payment systems seen in decades. Many policies are still being shaped, which is why it's critical that informed patients and health care providers continue to exert an influence on health care policymaking.

The history of advocacy for vulnerable patients is one of grassroots organizations drawing on the power of narrative—whether in the form of patients' own stories or providers' case studies—to inform critical policy changes on Capitol Hill and drive innovations in both health policy and care delivery. This article describes an example of such grassroots health care advocacy.

**A collaborative research initiative.** The product of a dialogue among congressional and federal policymakers, the Visiting Nurse Associations of America (VNAA), its Public Policy Council, the Visiting Nurse Service of New York (VNSNY), and a representative group of VNAA member organizations, this collaborative research effort has emerged as an effective model of public-private partnerships that can enable key health policy changes.

The research initiative sought to better qualify and quantify the characteristics of vulnerable home health care patients to improve our understanding of how patients interact with the Medicare home health reimbursement system. The organizations that performed the studies also sought to influence health policy to address these patients' needs. The partner organizations

mobilized to answer this question: Does the current Medicare home health reimbursement system adequately account for all the salient characteristics of vulnerable patients? In addition to answering this question, the initiative underscored the power of the case studies and grassroots home care organizations as agents of change for a health care system in transition.

## BACKGROUND

In 2009, the VNAA, under the direction of its Public Policy Council, began gathering case studies of vulnerable patients across the country to better understand and define patient vulnerability (see *Patients' Case Studies* for examples). In 2010, it expanded this work through more formal data collection and analysis. In collaboration with the VNSNY Center for Home Care Policy and Research, the VNAA conducted a pilot study that collected data on a range of patients treated by a small sample of member organizations. Chart reviews yielded data on clinical, resource utilization, payment, and nonclinical (social and environmental) factors that clarified what kinds of patients were adversely affected by the limitations in the Medicare home health prospective payment system (PPS). The scope of the data collected was purposefully broad—to ensure the capture of measures known to be related to resource utilization but that may not be adequately accounted for in the PPS. Patients' episodes of care, defined by the PPS as periods of 60 days (or less if the patient is discharged), were categorized into three groups based on cost and reimbursement: high loss, high margin, and breakeven. A total of nine agencies collected data from approximately 20 episodes in each of the three categories, with a final total of 531 episodes analyzed.

In 2012, the VNAA and its partners conducted a much more comprehensive study using data on more than 96,000 Medicare episodes involving 26 nonprofit

home health care agencies across the country (see *Characteristics of Patients Who Have High-Cost Episodes of Care*<sup>1,2</sup>). The data were supplemented with information from a sample of medical record reviews, the U.S. Census, cost reports from the Centers for Medicare and Medicaid Services (CMS), and characteristics about the agencies provided in Medicare Provider of Services Files.<sup>1</sup>

The VNAA and VNSNY undertook these studies to inform the CMS policymakers as they completed their own home health study (released at the end of

last year),<sup>3</sup> which was mandated in Section 3131(d) of the ACA.<sup>4</sup>

**Changes in payment policy.** The CMS has modified the payment policy for home health services several times over the past 20 years. One major change occurred in October 2000 with the implementation of the Home Health PPS, which altered the practice of reimbursing home health agencies on a cost-based, fee-for-service basis. Under the new system, the CMS reimburses certified home health agencies for episodes of care, and each agency receives a fixed payment for

## Patients' Case Studies

### The narratives that influence health care policy.

The following are examples of the kinds of case studies collected in 2009 as the first part of the Visiting Nurse Associations of America–Visiting Nurse Service of New York research initiative.

Ms. B., an 80-year-old patient living with acute respiratory failure, end-stage renal failure, and multiple pressure ulcers has required in-home hemodialysis for more than 10 years. Her husband has been able to provide the hemodialysis care for her, yet for one health care episode she needs 54 skilled nursing visits, 12 physical therapy visits, one visit from a social worker, and 52 visits from a home health aide to cover the rest of her care needs: wound care, pain management, respiratory assessment, caregiver teaching of a complex and changing plan of care, and other personal care services. The cost of this patient's care exceeds reimbursement by \$9,271 per episode—an extremely high cost to incur for Ms. B. or anyone else living with this condition on a daily basis. This financial burden is a reality not only for Ms. B. but for many chronically ill patients in the United States.

Another patient, a 62-year-old man, has had continuous home care for 13 years except for three hospitalizations. Battling the progressive nature of multiple sclerosis, this patient has also suffered several cerebrovascular accidents resulting in left hemiplegia and right leg weakness. The patient requires catheterization for neurogenic bladder and 12-hour split-shift home health aide support. His care plan is referred to as total care, meaning he relies on others for all his care needs. He is unable to stand, feed himself, reposition himself, bathe, or go to the bathroom independently. Physical therapy and occupational therapy are included in his care in the form of exercises and teaching the patient's caregivers to prevent unnecessary decline. On average, the cost of care for this type of patient exceeds reimbursement by \$538 in a 60-day period.

Mr. E. is 81 years old. He is a paraplegic with neurogenic bladder, a stage 4 pressure ulcer, and a new colostomy. A physician from the wound clinic of a local health care system has ordered Mr. E.'s home care. Although the local system has its own home care program, the agency did not admit this patient to its service. Mr. E. lives in a remote rural location, a 52-mile round trip for the home care staff. His orders include daily skilled nursing visits for wound care and ostomy teaching. A social worker has also been seeing this patient to connect him with community resources and transportation. Mr. E. is able to perform self-catheterization, but because of a history of urinary tract infections, he requires a new sterile catheter each time. The cost of this patient's episode of care exceeds reimbursement by \$4,733.

Ms. C., 79 years old, is a Spanish-speaking patient with complex comorbidities including diabetes, osteoarthritis, senile dementia with profound memory loss, and incontinence. She lives with her elderly husband, who is also vulnerable and frail with multiple chronic diseases including vision loss, cardiovascular disease, and anxiety, which renders him unable to care for his wife. A daughter is unable or unwilling to participate in the plan of care. The patient requires daily skilled nursing visits for insulin administration and diabetes monitoring. The nurse must also monitor her for skin breakdown and manage her medications, and a home health aide visits five days per week to provide personal care. The cost of this patient's episode of care exceeds reimbursement by \$5,842.

all services provided during this time period. The payment is based on the severity of patients' clinical and functional condition, as well as the therapy services they use.

After the PPS went into effect, the volume of rehabilitation services provided to Medicare patients increased significantly because the episodic payments were higher for patients receiving rehabilitative therapy. Consequently, the CMS has attempted to reduce incentives that may have encouraged patient selection aimed at serving those with more reimbursable rehabilitative needs and an unnecessary increase in the volume of therapy services provided. In 2008, the CMS implemented a major change in the payment system to

than English, unsafe neighborhood, poor health literacy, highly complex care needs, and lack of acceptance of the plan of care.

Because of the vulnerabilities they revealed, the patient case studies captured the attention of policymakers, and as a result, congressional and federal leadership encouraged the VNAA's Public Policy Council to engage in a more formalized and comprehensive analysis of the issue. Both Democratic and Republican staff of the House Ways and Means Committee and the Senate Finance Committee noted that adjustments to the PPS could not be made until a formal study demonstrated payment shortfalls for low-income, vulnerable patients.

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address the issue. This change incorporated a more graduated payment system based on utilization of therapy services. Unfortunately, while this revised approach reduced the visit-based therapy incentive by lowering the adjustment to episode rates, it continued providing payment for therapy based on the volume of therapy visits, which leaves intact the incentive to provide more therapy, albeit at a lower reimbursement rate. Moreover, it did not address another underlying problem with the payment system: its potential to underpay for the care of complex patients who may consume few therapy resources but require a high volume of nursing services (such as Ms. B. in *Patients' Case Studies*).

### IDENTIFYING PATIENT VULNERABILITY

The patient case studies collected in the first phase of the initiative were real-life accounts of the challenges frail and vulnerable patients face, narratives that could be presented to congressional and CMS policymakers to effect change in the imperfect reimbursement system that further marginalized those who were already most vulnerable.

Case reviews uncovered the following factors that affect patient vulnerability: inadequate or unavailable informal care, substance abuse history, unstable mental health status, poor structural adequacy of the home, lack of access to primary care, primary language other

### INFLUENCE AND IMPACT

In late 2014, the CMS released the *Medicare Home Health Study: An Investigation on Access to Care and Payment for Vulnerable Patient Populations*, which showed that caring for home health care patients who required parenteral nutrition, had traumatic wounds or ulcers, needed substantial assistance in bathing, or had social and personal conditions that limited access to care resulted in lower profit margins for home health agencies.<sup>3</sup> Further, treatment of patients admitted after acute or postacute stays or who had high clinical complexity based on the CMS's hierarchical condition category scores or certain poorly controlled clinical conditions, such as poorly controlled pulmonary disorders, was also associated with substantially lower home health profit margins. Many of these factors had been identified in the earlier efforts of the VNAA Public Policy Council's studies.

The responses to this work throughout the home health industry have been illuminating. Congressional and federal policy leaders have engaged with members of the VNAA community to consider the practical translation and implications of our work with regard to the people whom VNAA members serve. These organizations are front and center in the effort to improve patients' access to care at this critical time in health care transformation.

## Characteristics of Patients Who Have High-Cost Episodes of Care

The Visiting Nurse Associations of America–Visiting Nurse Service of New York study of more than 96,000 Medicare episodes of care, conducted by Rosati and colleagues and published last year in *Health Affairs*, identified the characteristics of patients whose treatment tended to have significantly lower reimbursement compared with cost.<sup>1</sup> Such patients

- lived in communities with lower median household incomes.
- had poorly controlled chronic conditions (for example, hypertension, diabetes, peripheral vascular disease).
- received respiratory treatments and therapies (for example, IV infusion therapy, parenteral nutrition).
- had clinically complex postacute and community admissions.
- had an overall status that was serious or frail.
- had problematic (higher stage) pressure ulcers.
- had urinary and bowel incontinence.
- lacked caregiver assistance for activities of daily living/instrumental activities of daily living, medication administration, or medical procedures.

Analysis also revealed that episodes of care for patients with these characteristics tended to involve more skilled nursing visits and fewer therapy visits compared with those for patients without these characteristics, indicating that the particular service needs of this population may drive costs higher.

These findings led the Visiting Nurse Associations of America to recommend that the Centers for Medicare and Medicaid Services closely examine “how clinical complexity and other characteristics of vulnerable populations affect reimbursement.”<sup>2</sup>

Three major achievements have come from this work. First, the findings of the studies conducted by the VNAA and VNSNY have been widely shared with grassroots providers, industry leaders, and national health care experts who are working to preserve access for vulnerable patients by limiting the cuts in payments proposed as part of the ACA. Second, both the methods and results of the VNAA-VNSNY studies have been shared with the CMS and helped inform the study mandated under Section 3131(d) of the ACA.<sup>4</sup> Third, the VNAA’s advocacy and research efforts continue to assist congressional and federal policymakers as they reexamine how best to deliver high quality care to those patients who have the particular combination of high clinical complexity and poor rehabilitation prognosis, as the existing method of calculating reimbursements for care provided to these patients represents a major deficiency in the current Medicare PPS.

The VNAA community played a vital role in persuading the CMS to consider the impact that clinical complexity and the resulting required nursing interventions have on clinical costs. Advocacy for the most vulnerable is a clear charge for mission-driven, community-based organizations.

The long-term impact of our studies remains to be seen, but the effort was successful in bringing congressional attention to the issue of patient vulnerability. As the community awaits the CMS’s ultimate policy decisions and as the rollout of the ACA continues,

we look forward to seeing reimbursement methodologies adapt to better meet the needs of the most vulnerable. ▼

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