Over-Medicalized Care at the End-of-Life in the United States: Addressing the Economic and Social Consequences

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Introduction

As the “graying” of America accelerates, and the concomitant, complex health issues increasingly impact our quality of life, there is a significant strain on families, health systems and health plan/payer resources. Roughly 10,000 baby boomers turn 65 every day, and about 10,000 more will cross that threshold every day for the next 19 years, flooding Medicare, Medicare/Medicaid (dual eligible), and the already beleaguered U.S. healthcare system. This so-called silver tsunami will be driven partially by advances in medicine that are helping people to live longer than in previous generations.

We now recognize that many individuals will experience some form of serious or advanced illness during later stages in life. It is evident that the sheer number of people likely to suffer with advanced illness is staggering: from those suffering with heart disease, stroke, diabetes, and COPD to Alzheimer’s or dementia, cancer or other life-limiting illnesses. In fact, from 2000 to 2050 the senior population is projected to grow by 135 percent, and aged 85 and over – the group most likely to need health and long-term care services – is projected to increase by 350 percent.

Advanced Illness occurs when one or more of these or other conditions become serious enough that general health and functioning begin to decline with little chance of recovery – a process that extends to the end-of-life. As their function deteriorates and the outlook for recovery dims, many of these individuals receive care that is fragmented, uncoordinated, or inadequate to meet their growing needs and personal wishes. Patients often suffer through unnecessary, even harmful treatments despite overriding expert opinion that, when patients have a terminal illness, at some point more disease treatment does not equal better care.
Given these circumstances, it is reassuring to witness the long-awaited emergence and receptivity to some form of integrated Advanced Illness Management (AIM) or community-based palliative care for this vulnerable population. Going forward, these appear to be the key components within population health programs that lead to the appropriate level of care for individuals and better quality of life for our elderly, frail population as well as their caregivers.

This white paper examines:

- The overall economic burdens of advanced illness at the end-of-life: a focus on age 65+ population, including important demographics, trends and economic factors. This includes the growing body of evidence around the recognition and management of advanced illness.
- Economic burdens and their impact upon patient, families and caregivers.
- Issues surrounding satisfaction levels among patients and caregivers.
- The role of AIM within Population Health Management as a potential solution to ease the economic burdens on these key stakeholders in the healthcare continuum. This includes a broader look at its application to hospitals as well as at-risk payers spanning Medicare, Medicaid, Medicare Advantage, Medicare/Medicaid Dual Eligible and Accountable Physician Groups and Accountable Care Organizations.

IDENTIFYING THE OVERALL ECONOMIC BURDENS OF ADVANCED ILLNESS:

Demographics, Data and Key Trends

By the year 2050, the proportion of the population that is over the age of 65 will increase to 20.3 percent. This trend will have a major impact on the organization and delivery of healthcare, particularly with the shift in focus from acute to chronic illnesses and the need to change from one-time interventions that correct a single problem to the ongoing management of multiple diseases and disabilities.

While the high prevalence of chronic disease has social implications, it is quite startling to review the economic costs of advanced illness at the end-of-life. Medicare beneficiaries
with multiple chronic conditions are the heaviest users of healthcare services. As the number of chronic conditions increases, so does the utilization of healthcare services and healthcare costs.

A pattern of intense spending and over-medicalization of an aging society has resulted in exorbitant costs for the healthcare system: approximately 35 percent of Medicare fee-for-service spend occurs in the last year of life, and the second to last year of life represents 13 percent of the total fee-for-service Medicare spend.9 One out of every four Medicare dollars -- over $125 billion -- is spent on care near the end-of-life.10 Overall, the five percent of the population with the highest spending was responsible for nearly half of all spending.11

A recent study looked at 2012 Medicare administrative claims data for older Medicare beneficiaries who died and identified four unique spending trajectories. Nearly half (48.7 percent) of older Medicare beneficiaries were classified as “high persistent,” maintaining high spending throughout the year.12

Another 10.2 percent showed a “progressive” pattern, starting low but increasing steeply. A third group, 29.0 percent of decedents, were “moderate persistent,” mimicking the “high persistent” pattern except for a spending dip a few months prior to death; and the final group, 12.1 percent of the sample, exhibited a “late rise” in the final four months of life after very low spending in the earlier months of that final year.

**Health care spending trajectories of medicare decedents in the last year of life.**

**SOURCE:** Author’s analyses of Medicare data, 2011-12.

**NOTE:** Spending is in dollars under a natural logarithm transformation.
This review of the overall cost burdens also merits a closer look at the term advanced illness -- especially as it relates to the Medicare population. While there are other models and modes of care for managing chronic illness – from primary care and Chronic Care Management (CCM) to Complex Care Management – the very definition of advanced illness points to the critical need for Advanced Illness Management (AIM).

Individuals progress into a stage of advanced illness when their clinical condition becomes resistant to treatment and they experience clinical decline with progression that is observable, definable and measurable. According to the Coalition to Transform Advanced Care, care decisions in advanced illness should be primarily driven by the values, goals and preferences of the individual who is ill and family members. They point out that people with advanced illness often undergo treatment in discontinuous episodes by multiple specialists in separate care settings.

There is growing recognition of the value of AIM as an important element of a population-based approach: outcomes and services are measured and valued at a population level rather than just service encounters between individual clinicians and patients. An expanded discussion of this model follows later.

**THE ECONOMIC TOLL ON INDIVIDUALS, FAMILIES AND CAREGIVERS**

High medical costs at the end-of-life do not only affect insurance plans and society. Patients with advanced illness, usually involving multiple chronic conditions, incur high emotional and financial costs, and the high cost of care also contributes to family stress. Out-of-pocket expenses for Medicare recipients during the five years before their death averaged about $39,000 for individuals, $51,000 for couples, and up to $66,000 for people with long-term illnesses like Alzheimer’s. For more than 40 percent of these households, the bills exceeded their financial assets.

The economic toll on caregivers and families is equally troublesome. There are 40.4 million unpaid caregivers of adults ages 65 and older in the United States. Of that group, nine-in-ten are providing care for an aging relative, and a plurality is caring for a parent, according to data from the Bureau of Labor Statistics. While caregivers are an important part of the care team in an increasingly patient-centric environment, there is insufficient training and support for this shift of medical care to the family caregiver, further eroding their earning potential. In many cases, caregivers have had no training to perform these tasks and have had to learn on their own.

During the last year of an ill person’s life, family caregiving averages nearly 66 hours per week, with increasingly expanded roles and responsibilities in caring for those with advanced illness. One study, in fact, reported an even greater number of hours: a statewide California study of caregivers of adults...
with cognitive disorders such as Alzheimer’s showed that caregivers provided an average of 84 hours of care per week, the equivalent of more than two full-time jobs.\textsuperscript{20}

This creates significant financial issues, with the pressures of long-term caregiving carrying even more severe consequences, especially for women. Informal caregivers personally lose about $659,139 over a lifetime: $25,494 in Social Security benefits, $67,202 in pension benefits, and $566,443 in forgone wages.\textsuperscript{21} Furthermore, caregivers face the loss of income of the care recipient, loss of their own income if they reduce their work hours or leave their jobs, loss of employer-based medical benefits, shrinking of savings to pay caregiving costs, and a threat to their retirement income due to fewer contributions to pensions and other retirement vehicles.\textsuperscript{22}

It is interesting to note that many caregivers of older people are themselves elderly. Of those caring for someone aged 65+, the average age of caregivers is 63 years with one third of these caregivers in fair to poor health.\textsuperscript{23} Older caregivers often spend the most hours providing care,\textsuperscript{24} and the amount of time spent caring increases substantially as cognitive impairment worsens.\textsuperscript{25}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure1.png}
\caption{Distribution of out-of-pocket spending in the last 5 years of life. Legend: *Expenditures for married include expenses of both spouse and household head.}
\end{figure}

PATIENT AND CAREGIVER SATISFACTION

Beyond these economic burdens, a clear understanding of what patients and families view as important at the end-of-life is integral to assessing their satisfaction with care and the success of improving the care of dying patients. There is a body of good evidence which suggests that the factors that are most important to patients and families at the end-of-life are: 27

- Pain and symptom management
- Preparation for the end-of-life
- Relationships between patients, family members and healthcare providers
- Achieving a sense of completion. 28

Spiritual care is also regarded as important by many patients and families at the end-of-life, 29 with cultural differences identified and appropriately addressed. 30

According to one study, there are a number of aspects that influence patient and family satisfaction with care: accessibility, co-ordination, and competence of healthcare services, quality of communication and relationships with healthcare providers, personalization of care, and support for decision-making. A meta-analysis of studies of end-of-life care showed that palliative care services improved satisfaction with end-of-life care. 31

Shared decision-making between clinicians and patients and their families is possible when all have an awareness of the patient’s approaching death. Advance care planning aims to encourage people to consider, discuss, and document their future wishes for care -- well in advance, if possible. It increases the likelihood of a good death -- one in which the patient’s needs, wishes and preferences can be addressed. 32 Discussing changing goals of care is an important part of this process. 33

The most effective end-of-life care is provided when there is this level of skillful communication with patients and families about realistic goals of care, and attention to understanding the patient’s and family’s concerns, 34 as well as competent symptom management. 35

One study concluded that palliative care and hospice services not only improve patient-centered outcomes

CAREGIVER-TO-PATIENT RATIO

The stark reality is that the ratio of caregivers to the growing number of frail individuals living with multiple chronic conditions and advanced illness is contracting. In 2010, there were 7.2 potential caregivers for every person age 80+. In 2030, that caregiver ratio will drop to four-to-one, and by 2050, the ratio will be less than three-to-one. 26
such as pain, depression, and other symptoms, but also patient and family satisfaction. This is accomplished by helping patients get the care they need to avoid unnecessary emergency department and hospital stays and shifting the locus of care to the home or community. The study also confirmed that palliative care and hospice reduce healthcare spending for America’s sickest and most costly patient populations.36

**POTENTIAL SOLUTIONS:**

Population Health and Advanced Illness Management present opportunities to identify at-risk patients and ease the economic impact of advanced illness.

In their quest to successfully address the myriad of challenges surrounding end-of-life care, health systems, at-risk payers, and accountable care organizations (ACO’s) are now seizing the opportunity to effectively integrate available community-based assets and resources into a structured and consistent population health management (PHM) strategy.

In meeting the Triple Aim of healthcare - improving the experience of care, improving the health of populations, and reducing per capita costs of healthcare - these stakeholders must identify patients earlier in the disease trajectory, intervene proactively to mitigate unnecessary healthcare costs and avoid burdensome, often unwanted, care.

While the tenets of PHM are applied across the care continuum – from wellness and primary care to chronic care and complex care management -- its application to Advanced Illness Management (AIM) or community-based palliative care is critical. The palliative care movement predated the AIM model, both in the acute and community settings. While the AIM model benefited from many of the early learnings associated with palliative interventions, it pivoted to a more medically-oriented approach to patient care, as opposed to the holistic model of palliative care.

Today, there is a new innovative blend of these models called Palliative Illness Management™ or PIM™, a subspecialty of population health which is particularly effective when powered by community-based palliative care providers. Analytics, systems and resources are put in place to ensure consistent adherence to best practices, as well as to support evidence-based guidelines, scalability and tracking/reporting to guide effective engagement and maximize quality of life outcomes.

This specialized solution incorporates predictive analytics to proactively identify patients with advanced illness and life-limiting diseases - those who are likely to receive costly, non-beneficial care during the final months of life. As pointed out earlier, with healthcare becoming longitudinally oriented rather than episodic, the greatest impact on optimizing post-acute care is to optimize pre-acute care, with earlier identification of at-risk populations and earlier
engagement in the disease trajectory. The more sophisticated tool-sets offer both “pre and post-acute analytics,” enhanced by field-based resources and consistent processes. This helps to avoid costly events such as hospitalizations or readmissions, and to optimize post-discharge referrals.

These patient identification strategies provide an underpinning that strengthens the PIM™ programs, and support an interdisciplinary team approach that includes both medical and non-medical care:

**IDENTIFY THE ISSUES**

Patients identified as appropriate for PIM™ benefit from conversations about goal-setting and advance care planning by trained palliative care providers skilled in having these conversations. These discussions should be proactive, well timed and integrated into routine care -- and revisited when a patient’s medical condition changes.

**CLOSE GAPS IN CARE**

Integrating PIM™ within the disease trajectory enables earlier intervention and engagement because it relies upon an interdisciplinary, medically directed team of healthcare professionals, including a physician, nurses practicing at the top of their license, home health aides, social workers, spiritual support and volunteers.

**ESTABLISH GOALS AND CARE PLANS**

In conjunction with the treating physician, the nurse and social worker-led palliative care team establish goals of care and develop care plans designed to support decision-making, measure and demonstrate the value of care to the patient, and enhance reporting to the healthcare system and payer.

**EXTEND CAPABILITIES OF THE PAYER POPULATION MANAGEMENT TEAM THAT TIE BACK TO THE MEDICAL HOME**

A field-based team of professionals with mobile technology-based tools can improve the scope, identification and efficiency of the program. When PIM™ platforms and associated resources to manage patients are integrated within a broader population health initiative, they provide a structured and consistent process with measured results: support better patient interactions and a streamlined on-boarding ramp for patients; include surveys, assessments and risk scoring; and ensure accurate reporting and performance metrics that are designed to match interventions with operational improvements and quality clinical and patient satisfaction outcomes.
One PIM™ program involving Medicare Advantage plan members, 200+ enrolled and 800 in the control group, demonstrated:

- Significant reductions in hospital admissions, and re-hospitalizations
- Reduced number of ICU days
- Drop in the average claims cost per member per month

Further, it shifts the center of care to the home or community, reducing healthcare spending for the nation’s sickest and costliest patient populations.

These results demonstrate that when new models combining AIM with palliative care are proactively delivered in the community, stakeholders can achieve more compassionate, affordable and sustainable high quality care.
The results of a member satisfaction survey generated exceptional results:

“5 out of 5 Star Ratings” on all:

- Comfort with PIM™
- Helpfulness managing the symptoms and stresses of illness
- Helpfulness to family and caregivers
- Satisfaction with PIM™
- Importance to patient that plan offers PIM™
- Likely to recommend
- Experience with PIM™ influence recommending plan

By tackling the most difficult aspects of disease understanding and quality of life, the PIM™ model ensures that gaps in care are identified and closed for this most vulnerable population. For payer-driven population health programs, this approach has a positive, significant impact on the overall healthcare burden, mitigating patient and caregiver financial consequences and improving member/patient satisfaction.

In doing so, the model successfully tackles the issue that the majority of Medicare beneficiaries with advanced illness and life-limiting diseases are not able to understand, let alone address, their own medical needs early enough in the disease trajectory.

### Palliative Illness Management™: PIM™

This merged model of care encompasses a four-pronged strategy in which resources are deployed to more thoroughly identify and engage at-risk patients who might otherwise go unnoticed by traditional means:

1) Utilizes healthcare practitioners -- predominately nurses and social workers -- to the highest level of their license, and leverages their individual expertise for efficacy and efficiency.

2) Taps into the expertise and synergies of existing community-based resources.

3) Relies upon both predictive analytics and on-the-ground (OTG) identification of members/patients.

4) Ensures that medical needs are rapidly escalated to engage with treating physicians or other medical resources, as appropriate.
Dealing with this challenge requires expertise that does not currently exist in general population health programs. Niche capabilities are required for conducting progressive and difficult conversations around quality of life in the remaining months of life.

According to four separate studies, palliative care at home demonstrated its effectiveness vs. the control groups:

- Healthcare costs DOWN 33 percent\(^{37}\)
- Inpatient Hospitalizations DOWN 43 percent\(^{38}\)
- Total Hospital Costs DOWN 30 percent\(^{39}\)
- Total Number of Hospitalizations DOWN 74 percent\(^{40}\)
- 30-Day Re-Hospitalizations DOWN 68 percent\(^{41}\)

**WHAT’S MORE:**

- 98% Completed Advance Directives v. 31 percent\(^{42}\)
- 100% Participated in Goals of Care Discussion v. 41 percent \(^{43}\)

**CONCLUSION**

There is a building sentiment across America that the aging population -- and the way we meet their challenges with advanced illnesses -- are either going to make or break us as a healthcare society.

Many are betting that success lies with long-term population health programs. As healthcare shifts from a fee-for-service (FFS) to value-based payment (VBP) models, and with recent payment changes and reforms stemming from CMS, effective PHM becomes more important than ever before. According to some industry reports, PHM is, in fact, the leading growth opportunity in a post-EHR healthcare era\(^{44}\) and has been identified as a major growth market for health investors.

Enter into this discussion, the spirit of innovation: the integration of AIM and community-based palliative care within population health programs. It’s a specialized approach expertly designed to address the burgeoning senior population and its burdensome experience with life-limiting illnesses. This represents a methodical, scalable mechanism that plugs into current PHM processes, bringing analytics and processes that tie into existing workflow. Essentially, it is a PHM power-booster, making PHM initiatives much more sophisticated and relevant to this vulnerable population.

As the nation’s health systems and payers strive to improve quality and reduce expenditures, a laser-focus on those with chronic, advanced illness is a strategic imperative. This is where it will be important to integrate non-medical assessment and services in conjunction with supporting medical resources.
It’s the raison d’être for introducing evidence-based palliative care and AIM models which have demonstrated greater patient satisfaction, higher quality and lower costs than traditional models.

By executing on a strategy that is holistic, data-driven, process-and-outcomes oriented, savvy decision-makers are embracing this brand of innovation to more effectively manage this at-risk population. This translates into greater costs savings for their organizations, emotional and financial relief for patients and their families, and a roadmap to successfully overcome some of the most critical challenges facing the U.S. healthcare system.
End Notes


4 AHIP, C-TAC.

5 AHIP, C-TAC.


13 AHIP, C-TAC.

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22 AARP, 2008.


**GREER MYERS**

President, Turn-Key Health and EVP, Chief Development Officer, Enclara Pharmacia

With more than 20 years of healthcare experience, Greer joined Enclara Healthcare in 2014, and maintains dual roles as its President of Turn-Key Health and its Executive Vice President of Corporate Development. Bringing strengths in post-acute operations, mergers and acquisitions, pharmacy benefits management, strategy and business development, he also has strong vertical experience in payer, provider and healthcare IT verticals.

Previously, he was the founder and CEO of the early stage end-of-life population health management company, Care Trajectory, LLC. He has also served as Vice President of Corporate Development for a national hospice platform company, where he was responsible for organic and acquisitive growth of the hospice operations, as well as EBITDA improvement activities related to major expense line items. Throughout his career, Greer has held various leadership roles: Managing Partner at AXON Strategy; Vice President of Business Development at TeleVox Software; and Vice President of Health Services and Development at Triton Health Systems / Viva Health.

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**ABOUT TURN-KEY HEALTH**

Turn-Key Health, a division of Enclara Healthcare, is an Advanced Illness Management (AIM) company for healthcare payers and at-risk provider organizations serving seniors. Its Palliative Illness Management™ (PIM™) model introduces a new option to improve care quality, address costs and reduce burdens associated with life-limiting illnesses. Visit www.turn-keyhealth.com