

Gauging the Experiences of the Seriously Ill in California: Analyzing Serious Illness Beyond Medicare Fee-for-Service

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Given the growing recognition of the need to improve care for individuals with serious illness, who frequently receive fragmented care¹ of varying quality² that does not reflect their goals, multiple payers have launched various serious illness programs. CMS has launched a Serious Illness Population track in the Primary Care First³ model and a High Needs Population track for its Direct Contracting⁴ model (described in a recently released request for applications⁵). Concurrently, Medicare Advantage (MA) plans are partnering with third-party firms⁶ and offering new supplemental benefits⁷ for services focused on their seriously ill members, whereas commercial insurers are establishing palliative care programs⁸ for their members.

However, most of the evidence driving these policies comes solely from the Medicare fee-for-service (FFS) program, largely due to restricted access to MA and commercial insurance claims data. This gives policy makers, providers, and health systems limited ability to understand how new initiatives are affecting overall care quality and individuals' experience and offers few opportunities to share best practices and expand the spread of successful models.

Limited evidence has been a key driver in why health systems and provider organizations are still early in their initiatives to improve serious illness care. In a recent survey⁹ of accountable care organizations, 94% reported that they were "partially" or "widely" identifying their seriously ill populations, but far fewer (only 8%-21%) were widely implementing serious illness programs (eg, home-based palliative care, 24/7 clinical access).

To help improve overall understanding of the characteristics of the seriously ill and build the evidence base, the Duke Margolis Center for Health Policy and the Integrated Healthcare Association (IHA) explored the distribution of the seriously ill in California with the support of the Gordon and Betty Moore Foundation (and with a team of advisors listed in the Acknowledgments). This type of state-level examination can help inform national discussion and future analytical work by showing key trends in serious illness, identifying where further work is needed, and clarifying where policy priorities should focus going forward.

How We Identified the Seriously Ill

It is difficult to identify individuals with serious illness in common data sources, as few sources commonly capture whether someone has a functional limitation. To overcome this, several experts have developed methods that use surrogates to identify the seriously ill using a multipart^{10,11} definition: (1) diagnosis of a significant condition (eg, 1 serious condition [eg, cancer] or 3 or more serious chronic conditions), (2) recent health care utilization (as shown through a recent hospitalization), and (3) surrogates for functional limitations (eg, usage of specific durable medical equipment [eg, home oxygen] or home health care, evidence of limitations in activities of daily living).

Researchers use these definitions flexibly depending on the sensitivity and specificity needed for a particular research question. We adapted this definition for the available claims

data from IHA's multipayer claims database managed by Onpoint Health Data, which included more than 15 million Californians with commercial insurance (both employer-sponsored and individual insurance), Medicare FFS, and MA. Given the data source, we slightly altered the list of diagnoses that were used in the first part of the 3-part definition (as noted in the [eAppendix](#) [available at [ajmc.com](#)]). The third part of the definition—which includes surrogates of functional limitation—was difficult to operationalize, partially because the durable medical equipment and home health surrogates were not easily available in the available commercial claims data and partially because the presentation of serious illness may look different in a younger population. Because of these issues, we found that including the third part of the definition (surrogates of functional limitations) made the seriously ill percentage extremely small, so we primarily present results in this article without the third part of the definition. We analyzed the state in 3 levels of detail: covered California rating regions (n=19), core-based statistical areas (n=26), and counties (n=58), with our primary analysis at the county level.

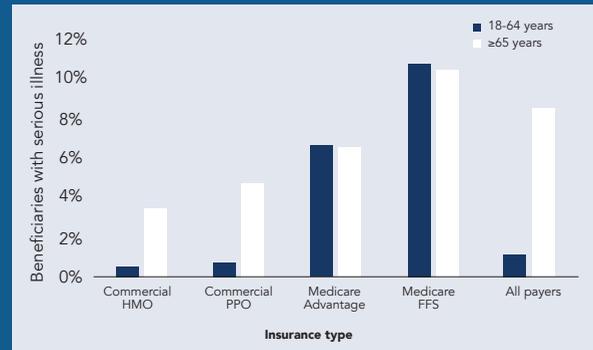
Do the Seriously Ill Look Different Across Insurance Plans?

This analysis examined the seriously ill for multiple insurance types and for different age cohorts (18-64 vs ≥65 years), with the results illustrated in [Figure 1](#). Access to this source of broader data allowed us to get a more comprehensive look at serious illness across the state of California, as many prior analyses of serious illness care have been restricted to traditional Medicare FFS data.

Not surprisingly, rates of serious illness tend to be higher in the population 65 years and older. However, the age differences varied by insurance type. For Medicare FFS and MA, serious illness rates were similar between the younger and older age groups, likely reflecting the fact that the group aged 18 to 64 years in those plans was primarily composed of individuals with permanent disabilities or end-stage renal disease. In contrast, serious illness rates were lower overall for individuals with commercial insurance, with large differences between younger and older cohorts for both types of commercial insurance (preferred provider organization [PPO] and health maintenance organization [HMO]).

In addition to differences between age groups, serious illness prevalence also differed by insurance types (PPOs vs HMOs; Medicare FFS vs MA). First, seriously ill individuals are more likely to be insured by programs with less restrictive policies, networks, and protocols, and broader networks are more valued by older individuals¹² and those with higher expected medical costs. The availability of the hospice benefit

Figure 1. Percentage of Members With Serious Illness, Broken Down by Insurance Coverage Type and Age^a



FFS, fee-for-service; HMO, health maintenance organization; PPO, preferred provider organization.

^aAuthor calculation. Used definition of serious illness based on diagnosis and utilization.

in Medicare FFS may also affect enrollment, causing the seriously ill to switch from MA to Medicare FFS to take advantage of that benefit.

Where Are the Seriously Ill Located?

Of individuals 65 years and older in California, 8.5% are individuals with serious illness (using our diagnosis and utilization definition). However, prevalence varies significantly across the state, ranging from 6% to 13%. As illustrated in [Figure 2](#), serious illness rates vary by payer, with serious illness prevalence for individuals 65 years and older looking different for all payers (right) compared with Medicare FFS (left).

The geographic analysis helps identify where future serious illness interventions should be targeted, based on prevalence and the quality of care for those individuals. For example, among urban counties in California, Los Angeles County stands out for its high prevalence of serious illness among the population 65 years and older in Medicare FFS. This may be because Los Angeles County has a high prevalence of dual-eligible individuals enrolled in Medicare FFS, although there are likely other sociodemographic and care pattern factors that influence these rates. Further localized hotspotting could allow for additional clarity in how and where interventions should take place, especially for larger counties like Los Angeles County, which has a larger population than 41 states.

How Do the Seriously Ill Utilize Health Care?

In general, we found that individuals with serious illness overall do not use different health care services than those

Figure 2. Percentage of Seriously Ill Individuals in California Counties Among Those 65 Years and Older^a



FFS, fee-for-service.
^aAuthor calculation.

without serious illness, but rather use more of them. For example, the top 10 most frequently filled prescription drugs for both the seriously ill and the non-seriously ill are overwhelmingly low-cost chronic disease management drugs such as statins and blood sugar control medications. The seriously ill population differs in that it has more prescriptions, uses more higher-cost drugs, and uses a wider range of prescriptions than the non-seriously ill.

Similarly, the seriously ill are far more likely to use hospital emergency departments (EDs). Seriously ill individuals 65 years and older had 1167 ED visits per 1000 members in 2017, whereas the non-seriously ill elderly had 251 per 1000. The disparity for the population younger than 65 years was even greater; the seriously ill averaged 1844 visits per 1000 members, whereas the non-seriously ill averaged 159 per 1000. The top reasons for ED visits were similar except that the seriously ill were diagnosed with sepsis for 4% of visits. Although most of these visits were not avoidable, the seriously ill have a much higher percentage of ED visits that were avoidable and could have been managed by primary care or other outpatient clinic visits. From these data, interventions to treat urinary disorders may be an ideal place for health systems to start.

Readmissions could also be a critical area of focus. The seriously ill group 65 years and older had 2.5 times more readmissions than the non-seriously ill, whereas the seriously ill population aged 18 to 64 years had 5 times as many. Given the strong focus on readmissions by many health systems, improvements in serious illness care could be an important component of any broader readmission reduction program.

Policy Implications

Our analysis offers key implications for policy in 3 areas. First, our analysis provides a tool that CMS and other states

could use to target, benchmark, and evaluate their serious illness initiatives. As noted earlier, the new Primary Care First-Serious Illness Population and Direct Contracting models offer new pathways for providers to improve serious illness care and could offer a bridge to more comprehensive approaches in the years to come. Future models could build on broader payment reform efforts¹³ to address long-term and expensive chronic care needs.

Secondly, this type of data could be useful for health systems and risk-bearing clinical entities as they seek to understand the seriously ill across all their patient populations (not just those with Medicare FFS). These could be cross-referenced with other data on population demographics, such as income levels, food insecurity, and environmental health. For example, a health system may identify that its seriously ill population consists mostly of individuals with serious cardiac conditions, such as stage D heart failure, and restructure its cardiology workflows and teams accordingly. It may focus on care management and reducing readmissions for this population and assess the impact on hospitalizations, ED visits, total cost of care, and readmissions. Smaller efforts would make it easier for organizations to make the business case, develop the necessary data infrastructure, and build an appropriate workforce necessary to deliver high-quality care.

Finally, studies like this one can use data to empower efforts to improve serious illness care in a particular county, which will require further study of what makes a county unique. Any number of reasons could contribute to challenges in serious illness care, including patient population, market dynamics, types of available providers, and geography. This will hopefully not just produce evidence but also be a first step in more extensive regional efforts to improve health care for the sickest populations.

Acknowledgments

This research was funded by the Gordon and Betty Moore Foundation. Karl Finison and Amy Kinner at Onpoint Health Data provided input on methodology and conducted the analytics to create a results file. The authors also thank collaborators who provided input and strategic guidance to the broader analysis, including Donald H. Taylor Jr, William Bleser, Jeffrey Clough, Arif Kamal, Gregory Daniel, Harriet Mather, Amy Kelley, David Muhlestein, Nathan Smith, Marissa Schlaifer, and Russ Montgomery.

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Source of Funding: Gordon and Betty Moore Foundation.
Author Disclosures: Mr Anderson presented at the September 2019 Rise West conference on risk adjustment. The remaining authors report no relationship or financial interest with any entity that would pose a conflict of interest with the subject matter of this article.

Authorship Information: Concept and design (DA, MJ, RS); acquisition of data (DY); analysis and interpretation of data (DA, DY, RS); drafting of the manuscript (DA, MJ, RS); critical revision of the manuscript for important intellectual content (DA, MJ, RS); provision of study materials or patients (DA); obtaining funding (DY); and administrative, technical, or logistic support (MJ).

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eAppendix

This analysis used the following approach to identifying people with serious illness, which was adapted from prior approaches. As noted above, some of these analyses only used the first two conditions (on diagnosis and utilization) and some used all three (adding in functional limitations).

1. Serious Medical Condition Requirement

This requirement is met by any of the following 3 subcomponents.

A. Having 1+ of the following severe conditions (identifiable using combinations of CCW codes):

- *Advanced liver disease, or cirrhosis (1 year)*
- *Breast, colorectal, endometrial, lung cancer (1 year)*
- *Chronic Kidney Disease Stage 5 or End Stage Renal Disease (ESRD) (1 year)*
- *Chronic obstructive pulmonary disease (1 year)*
- *Congestive heart failure (2 years)*
- *Diabetes with ischemic heart disease or peripheral vascular disease*
- *Hip fracture (1 year)*
- *Stroke / Transient Ischemic Attack (1 year)*

OR

B. Having 1+ condition in this category (as identified by the ICD codes¹ in the last pages of this document and attached spreadsheet):

- *Cancers with poor prognosis (solid with metastasis, or hematologic) (1 year)*
- *Dementia (2 years)*

OR

C. 3+ chronic conditions (any 3 of the following selected conditions below as defined by the common CCW codes):

- *Alzheimer's Disease CCW or Alzheimer's Disease and Related Disorders or Senile Dementia CCW (2 years)*
- *Acute myocardial infarction (1 year)*
- *Asthma (1 year)*
- *Atrial Fibrillation (1 year)*
- *Chronic Kidney Disease stage 3 or 4 (1 year)*
- *Depression (1 year)*
- *Diabetes (1 year)*
- *Ischemic Heart Disease (2 years)*
- *Osteoporosis (2 years)*
- *Rheumatoid Arthritis (2 years)*
- *Osteoarthritis (2 years)*

¹ This assumes the use of a validated algorithm of these codes to make sure to represent actual cancer diagnosis and not cancer screening. For example, some professional claims often include cancer diagnosis codes for cancer screenings but a validated algorithm would look for these claims paired with additional ICD codes within a certain amount of time or paired with the beginning of treatment.

2. Utilization Requirement

Have one inpatient hospital admission in the past twelve months

3. Functional Limitation Requirement

Having at least one of the following claims-based proxies for functional limitation

- *any Home Health utilization in the previous 12 months*
OR
- *any SNF utilization in the previous 12 months*
OR
- *any DME claim in the previous 12 months for home oxygen OR hospital bed OR wheel chair*