

# The Myth Regarding the High Cost of End-of-Life Care

Health care reform debate in the United States is largely focused on the highly concentrated health care costs among a small proportion of the population and policy proposals to identify and target this “high-cost” group. To better understand this population, we conducted an analysis for the Institute of Medicine Committee on Approaching Death using existing national data sets, peer-reviewed literature, and published reports. We estimated that in 2011, among those with the highest costs, only 11% were in their last year of life, and approximately 13% of the \$1.6 trillion spent on personal health care costs in the United States was devoted to care of individuals in their last year of life. Public health interventions to reduce health care costs should target those with long-term chronic conditions and functional limitations. (*Am J Public Health*. 2015;105:2411–2415. doi:10.2105/AJPH.2015.302889)

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**IN 2011, THE UNITED STATES** spent \$2.7 trillion on health care, more than double what was spent in 2000.<sup>1</sup> It is projected that, by 2040, 1 of every 3 dollars spent in the United States will be spent on health care.<sup>2,3</sup> Health care reform debates frequently highlight highly concentrated health care costs among a small proportion of the population and promote policy proposals to identify this “high-cost” group and significantly reduce its costs. Indeed, a wide range of programs are attempting to target chronically ill and complex patients with cost-effective interventions.<sup>4–10</sup> Yet, there exist no national, comprehensive patient-level data on the health care expenditures of the US population from which to estimate the expenditures of the high-cost group. Lack of comprehensive data is the primary reason detailed analyses of this high-cost group have not been conducted and why misperceptions about this group are common.

The discussion regarding the high-cost population in the United States has often focused on the population at the end of life, relying on evidence suggesting that those at the end of life drive health care spending.<sup>11–17</sup> This evidence is biased, however, in that most studies have examined only Medicare expenditures and, therefore, only the Medicare population. Although health care for older adults is generally more costly and the majority of costs in the last year of life are paid by Medicare, such analyses exclude the substantial health care costs paid by Medicaid, private insurers, and individuals themselves. Furthermore, whereas on an individual basis the last year of life may be significantly more expensive

than preceding years,<sup>18,19</sup> between-individual differences in health care costs at any stage in life outweigh within-individual differences. These substantial limitations of the existing evidence characterizing the high-cost population in the United States may have hindered policymakers’ attempts to rein in health care costs.

Here we address this important gap in our understanding of the high-cost population in the United States by providing estimates of total spending among those in the last year of life and describing 3 distinct subgroups within the “high-cost” patient population. Our analyses consider contributions from a more comprehensive set of payers than those included in prior studies. Because “total spending” data representing all payers do not exist in a single population-based source, our estimates draw upon a combination of data from existing national data sets (including the Medical Expenditure Panel Survey [MEPS] and the Health and Retirement Study), the peer-reviewed literature, and published reports. We also describe the persistence of health care spending across 3 major subsets within the high-cost group. In our opinion, the ability to design policy solutions that target individuals with exceptionally high health care costs is contingent on understanding the characteristics that define this population and, thus, how and why they incur such high costs.

## EXPENDITURES ALLOCATED TO THE LAST YEAR OF LIFE

To estimate total annual health care expenditures for the US

population, we started with data from the 2011 MEPS, the most comprehensive data set of annual health care expenditures for the community-dwelling US population. An important limitation of the MEPS data, however, is that the sample base represents the civilian, noninstitutionalized population and thus excludes residents of long-term care (LTC) facilities. To address this omission, we separately estimated the total annual health care expenditures for LTC facility residents as the sum of expenditures for the care of residents by facilities and expenditures for the care of residents outside of facilities, such as during hospital stays. These estimates were calculated with data from the 2011 National Health Expenditure Accounts,<sup>1</sup> adjusted according to the methods of Sing et al.<sup>20</sup>

We therefore estimated total health care expenditures for the US population in 2011 as \$1627 billion on the basis of 2011 MEPS data<sup>21</sup> (\$1330 billion) and our estimate of expenditures for LTC facility residents (\$297 billion). (Our estimate of \$1.6 trillion is lower than the National Health Expenditure Accounts estimate of \$2.7 trillion, which included expenditure categories unrelated to patient care such as government administration of health care programs, public health initiatives, and revenue from gift shops and hospital cafeterias.)

Of the \$1627 billion spent on health care in 2011, we estimate that approximately 13%, or \$205 billion, was devoted to care of individuals in their last year of life.<sup>22</sup> We used the Health and Retirement Study cohort to estimate the

cost of care for individuals in their last year of life paid by Medicare<sup>23</sup>; adjusted the estimate to reflect the additional 39% of costs in the last year of life that are paid by Medicaid (10%), out of pocket (18%, primarily for nursing home care), and by other sources including private payers (11%)<sup>11</sup>; and then used the Bureau of Labor Statistics Consumer Price Index to further adjust the estimate to 2011 dollars. We subsequently applied this estimate of per-person costs in the last year of life to the total number of deaths in 2011.

### ILLNESS TRAJECTORIES IN THE HIGH-COST POPULATION

The distribution of health care expenditures for the US population consistently exhibits a significant “tail” segment of the population with extremely high costs. Our analysis identified 18.2 million individuals in the top 5% of total annual health care spending who incurred average annual health care expenditures of \$17 500 or more per person and accounted for \$976 billion in health care costs overall. Of these estimated 18.2 million individuals (5% of the population) who generate the highest annual costs, only 11% (2 million individuals) are in their last year of life (Figure 1).<sup>24</sup> Longitudinal analyses of spending<sup>17,25,26</sup> show that the population with the highest annual health care costs can be divided into 3 broad illness trajectories:

- individuals who have high health care costs because it is their last year of life (population at the end of life),
- individuals who experience a significant health event during a given year but who return to stable health (population with a discrete high-cost event), and

- individuals who persistently generate high annual health care costs owing to chronic conditions, functional limitations, or other conditions but who are not in their last year of life and live for several years generating high health care expenses (population with persistent high costs).

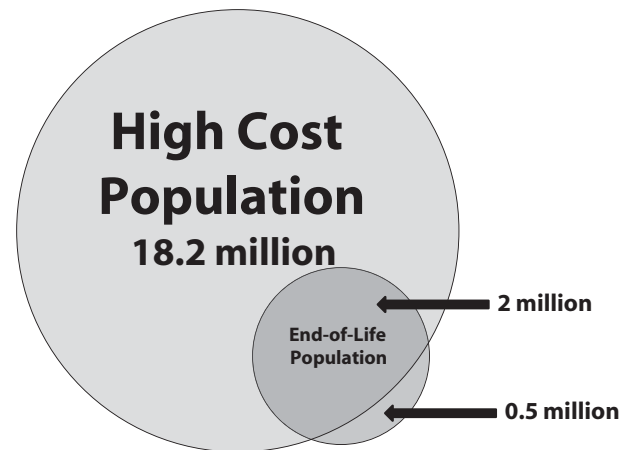
#### Population at the End of Life

We found that of the 18.2 million individuals who were in the highest 5% of the population in terms of total health care costs, 11% (2 million) were in their last year of life. These 2 million decedents represented 80% of the 2.5 million annual deaths in the United States in 2011. Conversely, the remaining 20% of decedents (0.5 million) did not incur the highest health care costs in their last year of life.

#### Population With a Discrete High-Cost Event

We estimated that the largest proportion of the population with the highest annual health care expenditures (49%) consisted of individuals who experienced a discrete event generating significant health care costs in 2011. We used evidence from a recent study<sup>17,26</sup> focusing on the persistence of spending patterns over time that showed that 62% of individuals in the top 5% of health care spending in a given year were no longer in the top 5% of spending the next year. A portion of these individuals died; the remainder transitioned to the bottom 95th percentile in health care spending the following year.<sup>17,26</sup>

Some examples of this illness trajectory might include people who have a myocardial infarction, undergo coronary bypass graft surgery, and, after a period of rehabilitation, return to stable health; individuals who are diagnosed with



Source. Total population and health care costs were obtained from 2011 Medical Expenditure Panel Survey data<sup>21</sup> adjusted to include the nursing home population.<sup>24</sup> The distribution of total costs for the end-of-life population was estimated from Health and Retirement Study data linked to Medicare claims data, adjusted to include non-Medicare payers<sup>11</sup> and adjusted to 2011 dollars via the Bureau of Labor Statistics Consumer Price Index.

**FIGURE 1—Estimated overlap between the population with the highest health care costs and the population at the end of life: United States, 2011.**

early-stage cancer, complete surgical resection and other first-line therapies, and achieve complete remission; and those who are on frequent hemodialysis while waiting for a kidney transplant and then receive a transplant and return to stable health. Once such an event has occurred, there may be relatively less opportunity for cost reductions in this population. Given that most of these individuals return to better health (as presumed by their lower costs) within a year, health care dollars may already be well spent. Policymakers must consider, however, that public health initiatives fostering healthier lifestyles and careful management of chronic disease might reduce the incidence of these discrete high-cost health events across the population.

#### Population With Persistently High Costs

The second largest proportion of the high-cost population (40%)

is those with persistently high health care costs. This subgroup is characterized by chronic conditions and functional limitations and tends to be older.<sup>25</sup> The existence of a subgroup of individuals with persistently high spending was evident in an analysis of Medicare beneficiaries showing that nearly half of beneficiaries who incurred high costs in 1997 incurred high costs in 1996 as well, and more than 25% also incurred high costs in the prior 4 years. Furthermore, 44% of these individuals continued to incur high costs in 1998 and 25% in 2001.<sup>27</sup> This is a key population for targeted interventions to reduce costs given that such interventions may enable cost reductions across multiple years.

#### LIMITATIONS

The limitations of our analyses are primarily attributable to the

fact that longitudinal data representing all payers in our health care system do not exist in a single population-based source, and thus we synthesized data and estimates from multiple sources for this analysis. First, note that MEPS data are limited to the civilian noninstitutionalized US population. To overcome this omission of the LTC population, we relied on other sources of health care expenditure data for nursing home residents.<sup>1,20</sup>

Second, our estimates of end-of-life costs are based on the fee-for-service Medicare beneficiaries included in the Health and Retirement Study. We hypothesize that this may have biased our end-of-life cost estimates toward higher results, a conservative approach for our study and one that may have overestimated the proportion of decedents among the most expensive 5% of patients.

Finally, our cost analyses did not include estimates for costs such as informal caregiving and lost wages. Consideration of these costs must be included in the context of any new or reformed health service design, as the economic implications of these costs

for our aging population are potentially profound.<sup>28</sup>

## POPULATION-LEVEL INTERVENTIONS

A substantial proportion of the high-cost group has persistently high costs,<sup>17,25,26</sup> underscoring the potential fiscal impact of targeting this group with high-value (i.e., high-quality and lower-cost) interventions. The challenge resides in appropriate prospective identification of this group. A recent analysis of US health care spending revealed that chronic illnesses account for 84% of total health care costs, but the group with chronic illnesses is extremely large.<sup>29</sup> Some evidence suggests that the presence of functional limitations in conjunction with chronic conditions is a better predictor of high health care costs than the number of chronic conditions alone.<sup>30</sup> The combination of chronic conditions and functional limitations may be associated with higher health care costs owing to the complexity of care coordination across multiple providers and settings, increased use of specialists and procedures, or an increased likelihood of hospitalization.

For example, a recent commentary<sup>2</sup> suggested that an estimated 22% of health care expenditures are related to potentially avoidable complications, such as hospital admissions for patients with diabetes with ketoacidosis or amputation of gangrenous limbs or for patients with congestive heart failure and shortness of breath due to fluid overload.<sup>2,31</sup> Furthermore, the disproportionately higher costs for this group may reflect a lack of adequate community-based care and supportive services, leaving patients with no alternative but to access the acute care hospital system by calling 911 or visiting the emergency department.

## ESTIMATED EFFECTS OF TARGETED INTERVENTIONS

In our opinion, our analysis suggests that identification of the appropriate target population for high-quality, cost-saving interventions is critical given the substantial variation in the size of different target populations, the costs generated by different populations, and the proportion of the target population likely to be affected by

a specific intervention. For example, using data regarding the population with chronic conditions and functional limitations<sup>30</sup> and our estimates with respect to the population at the end of life, we can imagine a hypothetical intervention and 3 potential target populations: individuals with chronic conditions and functional limitations, older adults with chronic conditions and functional limitations, and individuals at the end of life. If we assume, for instance, that the percentage of the target population that will be affected by the intervention is 50% and that the potential reduction in costs is 10%, we can compare between-intervention cost savings, as shown in Table 1.

An intervention that targets all individuals with chronic conditions and functional limitations (an estimated 45 million people), affects half of that population, and reduces costs by 10% will theoretically achieve nearly double the reduction in health care costs (\$45 billion vs \$27 billion) of an identical intervention that targets only adults aged 65 years and older with chronic conditions and functional limitations (22 million people). If the intervention targets all

**TABLE 1—Projected Cost Savings of Hypothetical Interventions for 3 Target Populations**

Target Population	Population Size	Total Cost, \$ (billions)	Hypothetical Intervention	Population Affected by Intervention, %	Potential Reduction in Health Care Costs, %	Potential Reduction in Health Care Costs, \$ (billions)
All individuals with chronic conditions and functional limitations	45 000 000	909	A	50	10	45
			B	50	5	23
Individuals aged ≥ 65 y with chronic conditions and functional limitations	22 000 000	543	A	50	10	27
			B	50	5	14
Individuals at the end of life	2 500 000	205	A	50	10	10
			B	50	5	5

Source. The percent distributions of populations and costs by age and chronic condition/functional limitation categories were obtained from The Lewin Group<sup>30</sup>; total population and health care costs were obtained from 2011 Medical Expenditure Panel Survey data<sup>21</sup> adjusted to include the nursing home population.<sup>1,20,24</sup>

individuals at the end of life (2.5 million), affects half of that population, and reduces costs by 10%, it will theoretically achieve less than a quarter of the reduction in health care costs (\$10 billion vs \$45 billion) of an identical intervention that targets individuals with chronic conditions and functional limitations (45 million people).

This projection highlights the fact that interventions aimed at individuals in their last year of life will generate smaller reductions in cost savings than interventions that target those with chronic conditions and functional limitations given the significantly smaller size of the end-of-life population and the limited time frame for cost reduction. In addition, given the complexity of identifying individuals in their last year of life relative to identifying individuals with chronic conditions and functional limitations, an end-of-life intervention may have an even smaller impact on costs than we have described because it would likely affect less than 50% of the terminal population.

## CONCLUSIONS

Maximizing value (i.e., increasing quality while reducing costs) in the care of high-cost, seriously ill individuals is a major public health challenge facing the nation's health care system and economy. Many proposals to reduce health care costs in the United States target the high cost of end-of-life care, yet at the population level the cost of caring for individuals in their last year of life accounts for only 13% of total annual health care spending. That is, although the majority of decedents are in the highest cost group, the majority of individuals in that group are not in their last year of life. Specifically, we estimate that only 11% of individuals

in the highest cost group are in their last year of life. Efforts to improve the quality of care for this group are clearly warranted<sup>25</sup>; however, expecting such interventions, if limited to those at the end of life, to have a meaningful impact on overall health care costs is misguided. Not only is this group small, but the window of time for a significant impact on costs is limited by the patients' life expectancy.

Furthermore, our findings confirm the need to focus on those with chronic serious illnesses, functional debility, and persistently high costs. Although many programs have begun to target segments of this population or evaluate health system and reimbursement models that may incentivize higher-value care,<sup>4-10</sup> outcome data and cost-effectiveness analyses are still forthcoming. Certainly, the greatest strides in improving the quality and containing the costs of health care for the highest cost population will be achieved by focusing research and clinical interventions on this vulnerable and complex group. ■

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## Contributors

The authors contributed equally to the study concept and design, analysis and interpretation of data, and the writing of the article.

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