

Implications of the Cost of End of Life Care: A Review of the Literature

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Introduction

Background

Introduction

Health care is an economic quantity that is different from most other goods. Access to and receiving health care could mean the difference between life and death. While health care is necessary throughout life, it becomes inevitable at the end of life. End of life itself has been defined as both a “state” (Riley and Lubitz (2010)) and a “stage” (Crippen and Barnato (2011), Bach (2011), Bach, Schrag and Begg (2004)). End of life care is extremely personal, expensive and complex as it impacts not only individuals, but their families and society in general.

Objective

The objective of this project is to summarize the existing literature on end of life issues of interest to actuaries, and to document a broad list of such articles. The end of life issues explored are multi-dimensional and from multiple perspectives. When considering cost implications of end of life care, it is necessary to consider cost in a broad context as it is a measure that cannot solely be defined by dollars. Other dimensions of cost, such as quality of care, family caregiving, communication, patient preferences and access to care, should also be explored.

Researchers

While we, Drs. Martin Halek and Marjorie Rosenberg, were the primary researchers on this project, we were significantly aided by the efforts of two actuarial science students, Jimmy Conway and Vignesh Valliappan.

Acknowledgements

We acknowledge support from the Health Section Research Committee of the Society of Actuaries for this research. We are grateful to the following members of the Project Oversight Group for their comments and suggestions: Russell Hendel, Prashant Nayak, Jeff Petertil, Brent Reis, Tim Rice, Tia Sawhney, Steve Siegel, David Strey and Sara Teppema. We also thank Barbara Scott from the Society of Actuaries for her assistance.

Methods/Process

Search Strategy

To find appropriate articles, peer reviewed journals were preferred, although non-peer reviewed publications and the popular press were also considered. For peer-reviewed literature, there were two primary approaches. First, the University of Wisconsin’s computer and library resources were employed to electronically search databases of journals on end of life issues based on various keyword terms. The following search terms were entered into PubMed, Ebscohost and Mary Ann Liebert, Inc.: end of life, terminal, terminal cost, end of life cost, palliative, palliative cost, terminal care economics and healthcare expenditure. Specific journals known to publish on end of life topics such as *Health Services Research*, *Journal of Law, Medicine and Ethics*, *Journal of Pain and Symptom Management* and *Journal of Palliative Care* were also specifically targeted. The other method used to identify articles involved examining the references of articles found via the first method. It was not uncommon to discover several related articles by following the citations of already selected papers.

Inclusion/Exclusion Criteria

Articles were selected based on relevance, timeliness, quality and contribution to examining all aspects of end of life care and costs. Often, many articles were identified that examined the same or similar issues, but were not summarized. The articles not summarized were included in a final list of citations. Moreover, there are certainly other articles on end of life care and costs that are not included in the list presented here; this is by no means an exhaustive list. While we had to apply some level of subjectivity in choosing which articles to include in the list of citations and which articles to summarize, we view this list as an indicative subset of relevant, quality end of life articles rather than a selection of the top or best articles per se. An article chosen by us resulted from a process of identifying the article (see *Search Strategy* above), considering its timeliness, and assessing its relevance and contribution to an end of life issue.

Structured Abstract Format

In summarizing selected articles, the intent was to provide objective information in a structured format without providing any critique. The summaries can be more readily compared by being in a common structure. To achieve this, each article was summarized as follows:

1. Formal citation including author(s), year, title, journal, volume, pages
2. Subject/Category
3. Key words
4. Number of references
5. Perspective of authors
6. Purpose of article
7. Data
8. Methods
9. Results
10. Limitations
11. Conclusions

Each summary was limited to two pages in length.

Resulting Articles

Number of Articles

There are 35 articles summarized and an additional 65 articles included in the final list of citations. As we had the citations for these additional articles, we included them for the interested reader.

Topics

There are many different subjects discussed in the articles that are summarized. Several articles address the challenge of clearly defining what end of life is or at least how it should be viewed or measured. Some articles explore how end of life costs impact individuals and their families. Other articles examine how end of life costs effect different demographics of society both in the United States and in other countries. Articles also discuss research design issues associated with examining end of life topics. Finally, several articles investigate topics related to end of life such as hospice care, palliative care, end of life preferences, communication and ethics issues.

Sources: Journals and publications (peer reviewed, non-peer reviewed and popular press)

The following is a list of journals and publications from which the summarized articles were selected.

Annals of Internal Medicine

British Medical Journal

Cancer

Health Affairs

Health Services Research

Journal of the American Geriatrics Society

Journal of the American Medical Association

Journal of General Internal Medicine

Journal of Law, Medicine & Ethics

Journal of Pain and Symptom Management

Journal of Palliative Care

Journal of Palliative Medicine

Journal of the Royal Society of Medicine

Palliative Medicine

New York Times

Social Science & Medicine

Remainder of document

The remainder of the document is organized as follows. A table of contents is provided which lists the titles of the 35 summarized articles organized by subject/category and year of publication. This is followed by the actual 35 summaries themselves. Finally, a list of citations for all 100 articles (those summarized and the additional articles) is provided and organized by subject/category and year of publication.

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Formal Citation

Hoover, D. R., Crystal, S., Kumar, R., U. Sambamoorthi and J. C. Cantor. 2002. [Medical Expenditures during the Last Year of Life: Findings from the 1992-1996 Medicare Current Beneficiary Survey](#). *Health Services Research* 37(6): 1625-1642.

Subject/Category: Cost

Key Words: End of life, elderly, health care expenditures, Medicare, Medicaid

Number of References: 25

Perspective:

The article is coauthored by three health services research professors, one statistics research professor and a data analyst; all with the Institute for Health, Health Care Policy and Aging Research at Rutgers University.

Purpose of Article

The purpose of the article is to compare aggregate and subdivided medical expenditures for the elderly (aged 65 and older) over the last year of life with those for nonterminal years to better understand end-of-life cost.

Data

The study uses the 1992 to 1996 Medicare Current Beneficiary Survey (MCBS) data. Enrollees aged 65 and older as of January 1 of the MCBS calendar year were included. This is a panel survey of a complex weighted multilevel random sample of about ten thousand annual Medicare beneficiaries. A structured questionnaire is administered at four-month intervals to collect beneficiary medical costs by payer source and service. For facility residents, billing office workers are asked to provide information on charges and payments. Only total health care expenditures for a calendar year, or portion of the year a person survives, are recorded. Medicare costs are validated by claims records.

The MCBS divides medical expenditures by payer source and type of medical service. The study analyzes aggregate expenditures, Medicare expenditures and non-Medicare expenditures which may be paid out-of-pocket, by Medicaid, by private insurance or by private HMOs. The following medical service categories are also analyzed separately: inpatient hospital, outpatient hospital, prescription drugs, medical provider, home health care, dental services, hospice, facility (e.g., nursing homes) and institution (short term stay of less than one year in a facility).

Methods

Full terminal year medical expenditures were estimated as MCBS expenditures are only recorded for an entire calendar year (or portion the person was alive) rather than on a daily or monthly basis. Here, mean expenditures during the last 1, 3, 6, and 12 months of life were modeled with robust covariance linear polynomial models using data from those dying in the given MCBS calendar year. These models were fit for all participants, and separate models were fit for three age categories, 65-74, 75-84 and 85+ years. Results of these models were used to estimate (1) mean expenditures for the last 12 months of life, (2) overall mean calendar year expenditures for all subjects, (3) mean portion of the sample dying annually, and (4) the variances and covariances of these estimates. Finally, these four aforementioned estimates allowed point

estimate and 95 percent confidence interval calculations for total (annual) expenditures for terminal and nonterminal years, mean annual expenditures for nonterminal years, percent of all expenditures spent on terminal years, and an expenditure ratio (ratio of mean expenditures during terminal year to mean annual expenditures during nonterminal years).

Results

The mean total annual medical expenditures during the terminal year were \$37,581, consisting of \$23,739 in Medicare and \$13,842 in non-Medicare expenses (1996 dollars). The mean total last-year-of-life expenditures did not differ much by age at death. However, Medicare last-year-of-life expenditures were significantly lower, and non-Medicare last-year-of-life expenditures were significantly higher, for those dying at older ages. The mean total annual medical expenditures for nonterminal years were \$7,365, consisting of \$3,775 in Medicare and \$3,590 in non-Medicare expenditures. The mean total nonterminal year expenditures did differ significantly by age at death. Here, both Medicare and non-Medicare expenditures significantly increased with age. Moreover, Medicaid, out-of-pocket, and private insurance expenditures were substantially higher during the terminal year compared to nonterminal years. Inpatient care, facility and medical provider were the leading expenditures for both terminal and nonterminal years of life.

Based on the average 1992 to 1996 Medicare beneficiary population size for those aged 65 and older, this group incurred about \$282 billion in annual national medical expenses, of which 22% was spent during terminal years of life. A significantly higher portion of Medicare expenditures (26 percent) relative to non-Medicare expenditures (18 percent) were from terminal years. When payer is considered, the expenditure ratio is highest for Medicare and Medicaid expenditures and lowest for HMO and supplemental insurance. Among services, an estimated 87 percent of hospice, 43 percent of institution, 30 percent of inpatient care, and 25 percent of facility expenditures went to terminal years of life.

In examining incremental months of terminal-year-of-life expenditures, about 30 percent, 51 percent, and 71 percent of all terminal year expenditures occurred during the last 1, 3, and 6 months of life, respectively. These proportions were higher (lower) for younger (older) age at death. For Medicare (non-Medicare) expenditures, these percentages were 38 percent (18 percent), 56 percent (36 percent), and 74 percent (59 percent), respectively. Medicaid expenditures were distributed quite evenly throughout the terminal year of life while 51 percent of terminal year inpatient care and 36 percent of hospice care payments occurred in the last month.

Limitations

The authors note that many MCBS expenditures are based on patients' self-reports and proxies; some of which can be confirmed (e.g. Medicare expenditures) while others cannot (e.g. non-Medicare expenditures). For the latter, the authors believe their validation methods and polynomial models yield reliable estimates.

Conclusions

The authors feel that while health services delivered near the end of life will continue to consume large portions of medical dollars, the portion paid by non-Medicare sources will likely rise as the population ages. Indeed, current mean out-of-pocket expenditures of over \$5,000 for the terminal year can create a substantial financial burden for many families. Policies promoting improved allocation of resources for end-of-life care may not affect non-Medicare expenditures, which disproportionately support chronic and custodial care.

Formal Citation

Riley, G. F., and J. D. Lubitz. 2010. [Long-Term Trends in Medicare Payments in the Last Year of Life](#). *Health Services Research* 45(2): 565-576.

Subject/Category: Cost

Key Words: Costs, Medicare, elderly

Number of References: 33

Perspective: The article is written by public health researchers.

Purpose of Article

The purpose of the article is to provide a descriptive analysis of possible trends from 1978 to 2006 on the amount and distribution of Medicare payments by type of service for individuals during their last year of life.

Data

The article utilizes annual Medicare claims data on a five percent random sample of the Medicare population contained in the Continuous Medicare History Sample (CMHS) from 1978 to 2007 (the years 1998-2000 are excluded due to a programming error). Data are restricted to Medicare beneficiaries aged 65 and older and not enrolled in managed care.

Methods

For each calendar year, fee for service Medicare payments are classified as either decedents in their last year of life or survivors. These payments are categorized by type of service: inpatient hospital, intensive care unit, coronary care unit, physician and other medical, outpatient, hospice, skilled nursing facility and home health. The percent of payments going to decedents or survivors in each year are adjusted by age, sex, and survival status of the 1978 sample to account for changes in the Medicare population and allow comparisons over time. Annual payments are also inflation adjusted to 2006 using the Consumer Price Index. These data are used to construct death rates, percent of Medicare payments going to persons in their last year of life, hospital utilization rates and percent of payments for each type of service. Results for decedents and survivors are compared over the sample period.

Results

From 1978 to 2006 the share of Medicare payments allotted to individuals in their last year of life decreased from 28.3 percent to 25.1 percent. The crude death rate among elderly Medicare beneficiaries remained around five percent, however; the average age of decedents rose from 78.7 to 81.9. Decedents who were hospitalized in their last few months remained around 63 percent; whereas the percent with multiple hospitalizations increased from 20 to 27 percent. Compared to decedents, survivors had substantially lower and more stable hospital utilization rates. The percent of survivors who were hospitalized at least once was around 17 percent while those who incurred multiple hospitalizations remained about 5.5 percent. The distribution of type of service obtained by both decedents and survivors significantly changed over the sample period. For both groups, inpatient hospital services accounted for a declining percentage of payments while outpatient, skilled nursing facility, and hospice care accounted for an increasing percentage. Throughout

the sample period, decedents had a larger proportion of payments for inpatient hospital and skilled nursing facility care compared to survivors, and a smaller proportion of payments for physician and outpatient care.

Limitations

The study does not include diagnosis-type data or data related to drugs from managed care or from nursing home. The study is made at an aggregate-level and does not study patterns by individuals.

Conclusions

The share of Medicare expenditures going to beneficiaries in their last year of life remained at just over 25 percent from 1978 to 2006. This result is despite changes in the delivery of medical care as exhibited by changes in the distribution of the types of services received by both decedents and survivors. Notably, for the elderly in their last year of life, there was an increase in both aggressive care (e.g. multiple hospitalizations) and nonaggressive care (e.g. hospice care). Factors that drive increases in health care costs have evidently affected the care of decedents and survivors in similar ways.

Formal Citation

Fassbender, K., Fainsinger, R. L., M. Carson and B. A. Finegan. 2009. [Cost Trajectories at the End of Life: The Canadian Experience](#). *Journal of Pain and Symptom Management* 38(1): 75-80.

Subject/Category: Cost, Canadian experience

Key Words: End of life, health care costs, health care trajectories, costs and cost analysis, trajectories of dying

Number of References: 12

Perspective

The article is co-authored by two research physicians and two health economists who were all affiliated with the University of Alberta as either faculty or clinical researchers.

Purpose of Article

The purpose of the article is to describe the patterns and predictors of health care utilization and costs for survivors as compared to decedents characterized by common trajectories. The authors believe that analyzing the possible relationship between trajectories of functional decline and health care utilization may lead to identifying cost implications as well as implications for health care services organization, financing, delivery, and evaluation.

Data

The article uses two years of administrative health-utilization data for three annual cohorts of permanent residents of Alberta, Canada (April 1999 to March 2002), identified by the Alberta Health Registry. Decedents' records and underlying cause of death are obtained from the Vital Statistics database. These databases are linked by names and dates of birth with an 88.2% success rate. Health-utilization costs, such as hospital and physician services, ambulatory care and prescriptions, are obtained from relevant Alberta Health and Wellness administrative databases.

Methods

For each of the three years, decedents are categorized on the basis of their underlying cause of death. Literature review, expert opinion and cluster analysis are used to categorize decedents according to sudden death, terminal illness, organ failure, frailty and other causes of death. Health-utilization costs are assigned to resources identified with appropriate adjustments applied when actual costs are not available. All costs are adjusted for inflation and denominated in 2002 Canadian dollars. Total health costs are decomposed into three components (the number of individuals who receive services within a given time frame, the dollar amount per service and number of services) to improve the precision of estimates and reveal more details about health-utilization and costs at the individual level.

Results

From 1999-2000 to 2001-2002 the annual number of deaths in Alberta increased slightly by 2.5% per year from 17,050 to 17,937. Each year about 6% of the deaths are categorized as sudden death while 26% of the deaths are attributable to each of the following trajectories: terminal illnesses such as cancer, organ failure and

frailty such as chronic heart disease. The remaining deaths are classified as either “other” (about 2%) or “unlinked” (about 12%) meaning these deaths cannot be linked to administrative records. Average costs for each trajectory increased over the three year period where the latest year costs were highest for organ failure (\$39,947) and terminal illness (\$36,652), followed by frailty (\$31,881) and sudden death (\$10,223). In examining the resources or sector of health-utilization, inpatient costs were primarily responsible for expenditures of all the trajectories, as much as 70% for terminal illness decedents, whereas long-term care contributed significantly to overall expenditures for organ failure and frailty decedents (up to 30%). Physician and ambulatory costs were proportionately greater for the sudden death group compared to the other decedent groups. Decedents utilized health resources more frequently relative to survivors, and at an average higher cost. For example about 87% of survivors see a physician at an average of 7.4 times per year, compared with 38.3, 34.1, 29.3, and 16.8 visits in the last year of life for terminal illness, organ failure, frailty, and sudden death decedents, respectively.

Cost trajectories that are observable by month for a two year period (broken into four stages) prior to death for decedents in Alberta in 2001-2002 illustrate differences in total expenditures across the four decedent groups. In the first stage (24-19 months), costs are relatively stable for all trajectories. In the second stage (18-7 months), costs for terminal illness approximately doubled but still remained below expenditures for the organ failure and frailty groups. In the third stage (6-4 months), expenditures increased markedly for all four groups with the highest growth rate attributed to the terminal illness group. In the final stage (3-1 month), costs almost tripled for the terminal illness and organ failure groups, whereas costs increased by factors of 3.6 and 2.4 for the sudden death group and frailty group, respectively.

Limitations

The data presented do not include the costs to informal caregivers or for social care. The results of the study do not provide information about the resources that are curative and those that are designed to ameliorate symptoms. Further, the results cannot be used to evaluate efficiency as that would require the incorporation of outcome data.

Conclusions

As in the U.S., in Canada a significant portion of health care resources are consumed by individuals at the end of life, typically defined to be the final six months of life as motivated by cancer patients. By examining differences in cost trajectories of categorized decedents over a two year period prior to death, the authors observe that costs are both distinct and significant beyond the final six months for non-terminally ill patients. Moreover, the authors argue that these differences demonstrate that costs are equally significant for non-terminally ill patients such as those suffering from organ failure or frailty. The authors believe these results may be used to shape future health policies as well as reduce health care costs.

Formal Citation

Levinsky, N. G., Yu, W., Ash, A., Moskowitz, M., Gazelle, G., O. Saynina and E. J. Emanuel. 2001. [Influence of Age on Medicare Expenditures and Medical Care in the Last Year of Life](#). *Journal of the American Medical Association* 286(11): 1349-1355.

Subject/Category: Cost, demographics

Key Words: Medicare data, last year of life

Number of References: 14

Perspective

The authors come from Boston University School of Medicine, U.S. Department of Veterans Affairs, Harvard Vanguard Medical Associates, National Bureau of Economic Research and National Institutes of Health.

Purpose of Article

The authors investigate the confounding of age as a covariate that helps explain the trend in Medicare expenditures in the last year of life.

Data

The authors use data of Medicare beneficiaries from the states of Massachusetts and California who died in 1996, using all decedents in Massachusetts and 20% of those in California. Participants included were enrolled in Medicare throughout the last year of life and were not enrolled in Medicare's End Stage Renal Disease program. The authors use the denominator file from the Health Care Financing Administration to merge with each state's 1996 death certificate files, matched by Social Security number, date of birth, date of death, and sex. Total insurance expenditure is calculated as the sum of Health Care Financing Administration payments. Insurance expenditures include acute hospitalizations, long-term hospitalizations, and skilled nursing home care, hospital outpatient, part B physician/supplier, home health care, and hospice, with data gathered from Medicare Provider Analysis and Review.

Methods

Expenditures during the last year of life are analyzed with respect to age, sex, race, and place and cause of death. Place of death is determined from the death certificate file; cause of death is determined according to the National Center for Health Statistics classification. The authors examine differences in expenditures between people who used any hospice and those who did not, and examine the influence of comorbidity on expenditures using the Charlson score to estimate comorbidity. Hospital expenditures are acute care hospitalizations only while physician expenditures include insurance payments for all types of physician services covered by the Medicare Part B insurance plan. Aggressiveness of medical care is estimated using two indices, one based on hospitalization (admissions including non-psychiatric ICU care) and the other based on use of selected aggressive services (ventilators, pulmonary artery monitors, cardiac catheterization, and dialysis). ANOVA tests are used for differences in expenditures or other outcomes across three categories. The Duncan test is used for pairwise differences between age groups. Finally, the authors perform a GLM analysis to assess the impact of age on costs.

Results

Medicare expenditures during the last year of life decrease with increasing age. Each additional year of age is associated with a \$413 decrease in cost in Massachusetts and a \$408 decrease in California. For all beneficiaries, the decrease in cost experienced with each additional year of age increases as the age of death increases. This pattern is consistent across sex and race, though expenditures for blacks are higher than for whites in all age categories. In both states, expenditures in the last year of life are highest for those who died in an inpatient setting, lower for those who died in a nursing home, and lowest for those who died in a residence, though the pattern of decreasing end-of-life cost with age is consistent across these sites. This pattern is also unaffected by cause of death and comorbidity.

Limitations

The data comes from only two states and may not be representative of the nation as a whole. The data does not include people in managed care programs or the Veterans Affairs medical program; using Medicare beneficiaries only may not be representative.

Conclusion

The authors find that the decrease in expenditures with age in the last year of life is in large part the result of less aggressive care with increasing age. Eighty percent of the decrease in total expenditures with age is accounted for by the decrease in expenditures for hospital services. Fifty percent of decrease in cost for hospitalization of beneficiaries who are hospitalized in their last year of life is much greater than the 30% decrease in the number of hospitalizations with increasing age, suggesting reduced intensity of care of the older groups during hospitalization. Also, the indices of aggressiveness used by the authors appear to confirm this conclusion.

Formal Citation

Shugarman, L. R., S. L. Decker and A. Bercovitz. 2009. [Demographic and Social Characteristics and Spending at the End of Life](#). *Journal of Pain and Symptom Management* 38(1): 15-26.

Subject/Category: Cost, demographics

Key Words: Country comparisons, literature review, palliative care, health economics, ethnicity, race

Number of References: 72

Perspective

The authors were employed at RAND corporation, the National Center for Health Statistics, and the Centers for Disease Control and Prevention.

Purpose of Article

The purpose of the article is to provide a review of existing literature on demographic and social characteristics and health care spending at the end of life in the United States, and discuss preliminary comparisons of end-of-life care spending in the United States with that in other countries.

Data

As a review of the literature, there is no direct use of data outside of the articles cited.

Methods

The authors review existing articles on the relationship between demographic and social characteristics and end-of-life costs.

Results

The authors summarize a number of characteristics, including age, race, gender, income, and country, examining the effect of each on spending in the last year of life. Ten percent of the U.S. health care budget, and about 27% - 30% of costs for those aged 65 and older, is spent on medical costs during the last year of life. Costs depend on the condition from which the patient suffers, with cancer and chronic obstructive pulmonary disorder being the most expensive. Medicare spending in the last year of life declines as age increases. Use of inpatient services is the primary driver of spending differences by age. Lower hospital costs at older ages may reflect reduced intensity of care.

Throughout their life, health expenditures for black people and other minority groups are often less than white people, and these disparities have been linked to higher mortality and morbidity. At the end of life, a shift in the pattern appears; black people are treated more aggressively than those who are white, and they are more likely to die in the hospital and less likely to use hospice. After adjusting for age (life expectancy for black people is 5.5 years less than white people) and other characteristics, racial spending differences are significantly different for those aged 80 and older. This difference is driven by use of inpatient services.

Especially in middle age, the use of health care services for nonelderly women and their spending on health care is considerably greater than those for men. Adjusting for men's shorter life expectancy, end-of-life

spending follows a similar pattern: more is spent on women than men, especially at younger ages. Medicare spends more on inpatient services for men and more on “social supportive” services (skilled nursing, home health, and hospice) for women.

After adjusting for age and other characteristics, Medicare spending in the last year of life was higher for those living in areas with the lowest median family income relative to those with the highest. Most regional variation in end-of-life spending cannot be explained by patient preferences; most Medicare beneficiaries prefer palliative care at the end of life as opposed to aggressive, life-extending care. However, the proportion of patients dying in hospital varies by region from 16% to 56% and hospice enrollment varies from 11% to 44%, after adjustment for age and other characteristics.

The fraction of Medicare spent on beneficiaries in their last year of life in the United States is comparable to that of the Netherlands but greater than in Switzerland. Costs from inpatient care dominate end-of-life spending across all countries studied. All countries experience a decline in end-of-life spending as age increases, with Taiwan seeing the greatest average decrease. In most countries, about half of those who die aged 65 – 74 do so in hospital; in Sweden the number is lowest, at about 25%. The likelihood of dying in hospital declines with age in all countries studied except England.

Limitations

The authors could not measure whether variations in end-of-life spending reflect differences in quality of care received rather than differences in clinical condition or patient preferences, perhaps as a result of cultural variation. In the United States, the data on end-of-life spending utilized for studies is mainly from Medicare, and excludes Medicaid, private insurance and out-of-pocket expenditures. The healthcare structure varies widely between other countries, further complicating the comparative study. Comparison of end-of-life spending across countries is also made difficult because of differences in populations sampled, components of spending included, definitions of end of life and time frames in which data were collected.

Conclusion

Medicare utilization is often subject to substantial variation at the end of life. The greatest source of variation appears to be age at death; however, there does appear to be substantial small area variation in end-of-life spending, even when controlling for age and other personal characteristics. The authors’ research showed similarities in relative spending by age across countries, suggesting that patterns of end-of-life care may be similar across different health care systems.

Formal Citation

Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., McIlwane, J., K. Hillary and J. Gonzalez. 2007. [Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care](#). *Journal of the American Geriatrics Society* 55(7): 993-1000.

Subject/Category: Cost, end-of-life preferences

Key Words: Palliative care, in-home services, patient satisfaction, end-of-life care

Number of References: 29

Perspective

The article is coauthored by four palliative care physicians, one gerontology researcher and four other contributors, all with Kaiser Permanente. The Kaiser Permanente Garfield Memorial Fund provided support.

Purpose of Article

The purpose of this article is to conduct a randomized trial to empirically examine the effectiveness of an in-home, community-based, palliative care program for terminally ill individuals based on patient satisfaction of care, medical care costs and proportion of patients dying at home.

Data

The analysis uses data from a randomized, controlled trial conducted in two states and using separate non-profit health maintenance organizations (HMOs) that provide integrated healthcare services. Eligible patients must have been terminally ill with a life expectancy of 12 months or less (based on primary care physician assessment), visited the hospital or emergency department at least once in the previous year and scored 70% or less on the Palliative Performance Scale (PPS). From September 2002 through March 2004, 718 patients were initially referred to the study, but 408 were excluded mainly because of failure to meet the aforementioned eligibility criteria. Hence, 310 patients were randomly assigned to receive either standard usual care (n=155) or receive standard usual care plus partake in an In-home Palliative Care (IHPC) program (n=155). Five usual care subjects withdrew from the study and eight IHPC group subjects died prior to receiving any palliative care. Data were collected on the final 297 patients within 48 hours of study enrollment and then every 30, 60, 90 and 120 days through phone interviews and from the HMO service utilization databases at each of the two sites. Specifically, demographic data, medical service utilization data (actual costs for contracted medical services and proxy cost estimates for all services provided within the HMO), service satisfaction data (Reid-Gundlach Satisfaction with Services instrument) and severity of illness information (PPS) were obtained.

Methods

Univariate descriptive statistics of patients are presented by HMO site (Colorado vs. Hawaii), by study group (usual care vs. IHPC) and in the aggregate. Differences between study group sample characteristics are analyzed using two-tailed *t*-tests for continuous variables and chi-square tests for discrete variables. Logistic regression is used to analyze constructed dichotomous satisfaction variables, and to analyze study group likelihood of dying at home. Differences in study group survival time are tested via Kaplan-Meier survival analysis, using the log rank statistic and censoring those who survived to the end of the study. Finally,

ordinary least squares (OLS) regression is used to examine the effect of the study group on the number of hospital inpatient days, the number of emergency department visits and medical care costs, controlling for the length of time enrolled in the program (survival) as well as demographic variables.

Results

For the entire sample, the average age is 74 (standard deviation (SD) 12), just over half are male, just over half are married, over one-third belong to an ethnic minority group, over one-third have more than a high school education, three-fourths live in their own home, three-fourths live with a family member and one-third have an annual income of \$20,000 or less. Just under half were referred to the study with a diagnosis of cancer. The majority of these demographic variables are similar across both HMO sites with the exception of Hawaii having a larger proportion of minorities. Moreover, there were no significant differences between the study groups in baseline measures (after study assignment) except for satisfaction with care where those in the IHPC group showed a significantly higher satisfaction with services. The vast majority of both groups were very satisfied with care throughout the study period, but the IHPC group consistently had a higher portion satisfied peaking at 93% at 30 and 90 days after enrollment. Also, 75% died during the study period with no significant proportional differences between study groups. Those in the IHPC program survived an average of 196 (SD 164) days compared to 242 (SD 200) days for those in usual care. Results of Kaplan-Meier survival analysis failed to show any significant difference in survival time between the study groups.

Bivariate analysis showed significant differences between the study groups in terms of service use, cost of care and site of death. The IHPC group frequented the emergency department and were hospitalized less than the usual care group, incurred lower medical costs than the usual care group and had a larger proportion die at home (71%) than the usual care group (51%). When controlling for survival, age and severity of illness, linear regression results showed that compared to the usual care group, the IHPC group reduced hospital days, emergency department visits and overall costs of care by 4.36, 0.35 and 33%, respectively. The adjusted mean cost of care and average cost of care per member per day for the IHPC group were \$12,670 (SD \$12,523) and \$95.30, respectively. The same measures for the usual care group were \$20,222 (SD \$30,026) and \$212.80, respectively. Finally, when controlling for survival, age and medical conditions, logistic regression results showed the IHPC group participants were 2.2 times as likely to die at home as those receiving usual care.

Limitations

The authors acknowledge several limitations. First, since the study was conducted within closed-system managed care settings, the authors state that the results may not be as applicable to all healthcare settings. Further, the use of proxy costs of care calculated from aggregated patient records limits the ability to generalize relative cost savings across settings. Second, the authors did not examine effects on patient outcomes of any individual components of the IHPC program. Third, the authors feel that knowing a patient's preferred location of death would improve the site of death preference measure. Finally, the authors note that the study was limited in the lack of accurate hospice data available at one of the HMO sites.

Conclusions

The authors suggest the results of their study, along with other studies that find similar results regarding the positive effects of palliative care, support the need for changes in the design of our healthcare system. They propose adjusting our current hospice benefit to better meet the needs of patients, or developing a new, "pre-hospice" palliative care benefit that provides a bridge between standard medical care and hospice care.

Formal Citation

Smith, T. J. and J. B. Cassel. 2009. [Cost and Non-Clinical Outcomes of Palliative Care](#). *Journal of Pain and Symptom Management* 38(1): 32-44.

Subject/Category: Cost, end-of-life preferences

Key Words: Palliative care unit, palliative care consult, cost savings, cost avoidance, nonclinical outcomes

Number of References: 42

Perspective

The authors are professors specializing in oncology and psychology at Virginia Commonwealth University.

Purpose of Article

The purpose of the article is to show that the addition of palliative care to a usual treatment course, while not profitable in itself, leads to marginal cost savings for the overall healthcare system through "cost avoidance", while maintaining or improving quality of care given.

Data

As a summary of previous studies, there is no direct use of data outside of the articles cited.

Methods

The authors review and compare previous studies on the effect of palliative care interventions on cost.

Results

In reviewing articles on seven randomized trials of the impact of palliative care on cost, the authors find cost savings from palliative care compared to normal care. For example, in seriously ill cancer patients, nurse coordination, in which a nurse consults patients over the phone, leads to fewer hospitalizations and cost savings of 41% with no effect on patient symptoms. Similarly, another study shows that when hospice care is concurrently added to oncology care, patients transition to hospice sooner, saving costs and reducing caregiver stress, again with no major difference in clinical outcomes. Two studies of patients in individual health systems show savings of \$4,855 per patient when interdisciplinary palliative care service is used. A randomized study of Kaiser Permanente patients shows that the addition of palliative care leads to fewer emergency room visits and a 33% reduction in costs.

In addition to cost savings, the studies examined show other consequences of palliative care. One randomized study finds that palliative care intervention increases the percentages of patients who die at home from 15% to 25%. The authors found that a modified palliative care system, with lower costs than full hospice, along with control over the clinical care of the patient, is associated with fewer hospitalizations, fewer intensive care unit (ICU) hospital days, and lower costs. Nonrandomized studies confirm the correlation between palliative care and reduced patient costs, even in large health systems.

Conclusions from studies relating palliative care to total length of stay in hospital are mixed. Some show shorter hospital stays with the addition of palliative care, some show no difference and one showed longer

stays. Other studies are less useful because they do not separate surviving patients from those who died. Some studies looked at the impact of palliative care on care intensity showing that patients receiving palliative care spent an average of 4.43 fewer days in the ICU.

Limitations

To date, most palliative care programs have not been required to keep track of much data, especially about outcomes. In order to clearly identify the true impact of palliative care, both clinical and economic, better data are needed, with patients randomized between usual and palliative care.

Conclusion

The authors' review finds that palliative care programs reduce average patient costs, release beds in the ICU and lead to reduced intensity of care. As previously mentioned, the authors see a need for more data on the impact of palliative care, with an emphasis on studying the effect on the whole healthcare system, not just individual programs or departments. These studies could help determine at which point and for which patients, palliative care should be presented as an option and actually implemented, whether consultative services have the same kind and degree of clinical and financial impact as dedicated units, and how payer incentives impact palliative care. The authors hope such studies can push to provide palliative care, when needed, to patients at the time of diagnosis, instead of immediately before death.

Formal Citation

Lantos, J. D., and W. L. Meadow. 2011. [Costs and End-of-Life Care in the NICU: Lessons for the MICU](#). *Journal of Law, Medicine & Ethics* 39(2): 194-200.

Subject/Category: Cost, ethics

Key Words: Cost, medical intensive care unit, neonatal intensive care unit, survival

Number of References: 35

Perspective

The article is co-authored by pediatric research physicians.

Purpose of Article

The purpose of the article is to compare neonatal intensive care units (NICUs) with medical intensive care units (MICUs) to increase understanding of the development of these units, and likely issues for clinicians, patients, and policymakers in the future.

Data

The factual and opinion-oriented nature of the article does not directly utilize any data. The article references related research based primarily on intensive care unit studies regarding survival rates, costs and treatments.

Methods

The article first describes the historical development of NICUs, and then discusses empirical results on costs and survival to better compare and contrast NICUs with MICUs. The authors ultimately offer researchers who focus on MICUs some cautionary lessons learned from their own experiences and studies on NICUs.

Results

Historically, concerns about the cost-effectiveness of NICUs have led to critical analysis of these units by physicians, economists and epidemiologists. Neonatology originates back to the late 19th century. The first seventy years of neonatology innovations centered on the “nursing” of premature babies (e.g. warm incubators, sterile milk) while medical advancements were fairly limited until the introduction of mechanical ventilation in the late 1960s. This significant innovation made it much easier to keep premature babies alive, but also made it much more difficult to know when or whether to let them die. This era also created regionalized centers for intensive care and collaborative research networks.

The frequency and cost of death and survival in NICUs can be measured in various ways. The median and average day of death for babies who die in the NICU is 7 and 18 days, respectively. NICU costs are approximately \$3,000/day. The cost of neonatal intensive care increases as infant gestational age decreases. On average, premature babies stay in the NICU until close to the time when they would have been born. The total cost per NICU survivor is a function of the cost per survivor, the cost per non-survivor and the percentage of the babies who survive. For infants born at 25 weeks, 24 weeks and 23 weeks, the survival rates are 60%, 40% and 20%, respectively; while the total costs per survivor are \$330,000, \$375,000 and \$500,000, respectively. Since more babies are born after longer gestational periods, the total cost to society of caring for

older premature babies (e.g. those born at 30 weeks) is greater than the cost of caring for less premature babies (e.g. those born at 24 weeks). There are medical expenses after discharge from NICU that also tend to increase as infant gestational age decreases. Prior research calculated quality-adjusted life years (QALYs) as \$8,000 per QALY, \$6,000 per QALY and \$4,000 per QALY for babies born less than 26 weeks, between 26 and 28 weeks and after 28 weeks, respectively. (The generally used threshold is \$50,000 per QALY where results below this threshold are deemed cost-effective.) Another dimension of cost considers expenditures on NICU survivors versus NICU non-survivors. Eighty-five percent of NICU expenditures are for babies who survive since those who survive stay in the NICU, while babies who die, die quickly. This contrasts sharply with MICUs where the most expensive patients, the ones who stay in the MICU the longest, are the ones most likely to die prior to discharge.

All ICUs would be more cost-effective if predictions on which patients will die and which survivors will be severely impaired could be improved. In the NICU, gestational age is a powerful predictor of neonatal death as survival rates steadily increase from 0% at 22 weeks to 90% at 28 weeks. There are not common protocols as to which factors are predictive of survival. The authors believe in an individualized prognostication based on consideration of both parental preferences and the accuracy of its prognostication.

Neonatology differs from adult intensive care along several dimensions. MICUs have hundred times more patients and hundred times more dying patients. NICU patients tend to have one of three primarily independent ailments: respiratory distress, feeding intolerance or congenital anomalies. The first two tend to be resolved over time while the latter can be treated. Adult MICU patients suffer from a wider variety of illnesses and the majority of these patients have serious co-morbidities that remain regardless of the length of stay in the ICU. Time is another dimension that differs across MICUs and NICUs. The longer an MICU patient remains after admission, the lower the odds of survival. The longer an NICU patient remains after admission, the higher the odds of survival. The most expensive NICU patients are the most cost-effective; whereas the most expensive MICU patients are the least cost-effective. In the MICU, patient autonomy dominates while in the NICU parental autonomy dominates. Finally, public policy and professional guidelines are not the same for MICU and NICU.

Limitations: The authors caution that research on both NICUs and MICUs often leads to biased conclusions about the efficacy and cost-effectiveness of these units because studies are based on selected subpopulations. The use of Medicare data serves as an example as it is limited to patients over age 65 and is observational data.

Conclusions

There exist many differences and parallels between NICUs and MICUs. Extensive research based primarily on survival and quality of life, including follow-up studies, on NICUs has shown them to be among the most cost-effective of all intensive care interventions. There are significantly fewer such evaluations on the cost-effectiveness of MICUs and almost no follow-up studies. Hence, the authors feel more rigorous analysis of MICUs is warranted. The authors also believe both NICUs and MICUs need improved prognostic tools in order to utilize resources more efficiently and reduce suffering by patients and their families. Prognostication of mortality and/or morbidity based on individual patients' responses to any initial ICU care remains the objective of cost-effective ICU care.

Formal Citation

Simoens, S., Kутten, B., Keirse, E., Berghe, P. V., Beguin, C., Desmedt, M., Deveugele, M., Leonard, C., D. Paulus and J. Menten. 2010. [The Costs of Treating Terminal Patients](#). *Journal of Pain and Symptom Management* 40(3): 436-448.

Subject/Category: Cost, international

Key Words: Costs, terminal patients, palliative care, health resources

Number of References: 22

Perspective

The article is coauthored by six research physicians and four health services researchers, all associated with various Belgian universities, hospitals and research institutes. The project received financial support from the Belgian Healthcare Knowledge Centre, a state-funded research institution.

Purpose of Article

The purpose of this article is to review the international research literature on the costs of treating terminally ill patients with a focus on the level, distribution and drivers of costs.

Data

As a review of the literature, there is no direct use of data outside of the data used in the cited articles. To compare costs between articles, costs were converted to 2007 values using a rate of inflation based on the Consumer Price Index, and using market exchange rates adjusted for differences in purchasing power between countries and Belgium. Due to heterogeneity of the primary studies, cost estimates were not pooled across studies, but were presented for each study separately.

Methods

The authors identified international studies by searching PubMed, Centre for Reviews and Dissemination databases, Cochrane Database and EconLit for articles published in peer-reviewed journals between 2000 and April 2009. Additionally, bibliographies of included studies were checked for other relevant studies. Only studies that either contrasted costs in different health care settings or that compared palliative care with alternative therapeutic approaches for terminal patients were included.

Of the 56 articles initially identified by the researchers, 41 were excluded because they either measured costs at the end of life rather than costs of terminal patients, they quantified health care resource utilization but did not convert it into costs or they carried out an economic evaluation rather than a cost study. The authors place each of the remaining 15 international articles into one of the following three costs categories: 1) costs of treating terminal patients across health care settings, 2) costs of treating terminal patients in hospital, and 3) costs of treating terminal patients at home. Details of characteristics (e.g., sample size, study design, data collection, interventions) of all the articles are presented in a table and detailed descriptions of each article are discussed.

Results

Overall, there were only two articles on the costs of treating terminal patients across health care settings as the researchers found few studies that calculated palliative care costs across hospital, outpatient and home care settings. These two studies found that hospitalization costs represent the principal component of palliative care costs. Seven articles compared costs of different end of life care within hospitals such as palliative care costs compared to usual care costs or intensive care unit costs, and providing inpatient palliative care consultation or not. Results of the seven studies consistently indicated that palliative care was cheaper (lower costs and lower use of resources) than usual care or care delivered in hospital units other than the palliative care unit. Finally, the authors reviewed six articles that compared costs of different end of life care programs, such as palliative care programs, that were administered at patients' homes. Here, the authors noted evidence pointing to cost advantages of palliative care at home, although this needs to be further corroborated by further research.

Limitations

There are no limitations discussed by the authors.

Conclusions

The authors believe the cost estimates and methodological perspective provided may serve to determine priorities for and inform future research on terminal patients, and may be used in future economic evaluations exploring the cost-effectiveness of various care models for terminal patients. The authors claim their analysis supports the policy recommendation that hospitals need to pay attention to admitting patients to the palliative care unit at the right time from a cost perspective.

Formal Citation

Barnato, A. E., McClellan, M., B., C. R. Kagay and A. M. Garber. 2004. [Trends in Inpatient Treatment Intensity among Medicare Beneficiaries at the End of Life](#). *Health Services Research* 39(2): 363-375.

Subject/Category: Cost, treatment trends

Key Words: Medicare, end of life, elderly, health care expenditures, intensive care

Number of References: 15

Perspective: The article is coauthored by four research physicians; two of whom are also health economists.

Purpose of Article

The purpose of the article is to investigate whether increases in inpatient treatment intensity for Medicare decedents account for increases in end-of-life inpatient expenditures between 1985 and 1999. Over the same time period, the proportion of Medicare beneficiaries receiving hospice care and home health care prior to death increased while the proportion receiving acute hospital care decreased.

Data

The study uses the Medicare Medical Provider Analysis and Review (MedPAR) files for every other year beginning in 1985 and ending in 1999. The sample includes information on acute care hospital claims for a random 20 percent of all Medicare decedents and a random 5 percent of all Medicare survivors. Both groups include only those Medicare beneficiaries older than age 65 who were alive on January 1 of the calendar year, resided in the United States, were continuously enrolled in Medicare Part A or Part B during the year and were not enrolled in a managed care plan at any point during the calendar year. For decedents, claims were tracked for 365 days prior to death while for survivors claims were tracked for the calendar year. The sample contains almost 1.5 million beneficiaries per year.

Methods

Age-, sex-, and race-adjusted summary statistics for hospital and intensive care unit (ICU) use, inpatient procedure use, and hospital expenditures for decedents and survivors are presented. Data are reported on 88 intensive inpatient procedure categories that were likely the primary reason for admission. Beneficiaries are described as having one or more hospital admission, ICU admission, or intensive procedure. Hospital expenditures are calculated using Medicare diagnostic related group (DRG) reimbursement plus per diem and outlier reimbursement as listed on each hospital claim. Expenditures are reflected in 2000 U.S. Dollars using the gross domestic product (GDP) inflation index. Medicare beneficiary survivors are used as a basis to account for secular increases in treatment intensity among all patients in the U.S. over this time period. Here, decedent-to-survivor (D:S) ratios on expenditure and utilization metrics are created to reflect relative changes over time. An increase (decrease) in a D:S ratio implied that growth among decedents (survivors) was greater than among survivors (decedents).

Results

In the aggregate, from 1985 to 1999 real inpatient expenditures for the Medicare fee-for-service population increased by 60 percent from \$58 billion to \$90 billion where one-quarter went to decedents. In this study in

1985, expenditures attributable to hospitalization for the 88 intensive procedure groups accounted for 28 percent and 37 percent of total inpatient expenditures for decedents and survivors, respectively. These percentages increased to 45 percent for both groups in 1999. Utilization trends were mixed for both groups. The percentage with one or more hospital admissions during the year remained similar, however; for those admitted at least once, the number of admissions per person increased while the length of stay decreased. Total per capita ICU use, the percent who underwent one or more intensive procedures and the mean number of intensive procedures increased for both groups. A decedent was more likely than a survivor to undergo any intensive procedure and more decedents received aggressive end-of-life care procedures (e.g., intubations and tracheostomies). Overall, more intensive, costly procedures were performed on survivors than decedents.

Relative changes in expenditures and inpatient treatment intensity were also mixed. While overall per-capita expenditures remained just under six times more for decedents than survivors from 1985 to 1999, the D:S ratio of expenditures attributable to hospitalization for intensive procedures increased by about 31 percent, suggesting that procedure-attributable spending increased faster for decedents than survivors. D:S ratios for hospitalization, claims per person hospitalized at least once and per-capita rates of one or more intensive procedures remained constant, however, the mean number of intensive procedures received by decedents relative to survivors increased. D:S ratios for length of stay and ICU admission decreased.

Finally, between 1985 and 1999, the mean age of fee-for-service decedents increased by about two years which reflects both improved life expectancy and a shift of younger beneficiaries into managed care plans.

Limitations

The authors acknowledge several limitations. First, they note that trends in outpatient or non-acute-care hospital expenditures and treatment intensity may differ from those observed in this study of inpatient services. Second, they believe their measures of utilization generally underestimated actual treatment intensity because several rate metrics are defined as “one or more” (e.g., hospitalization, ICU admission and intensive procedure). Third, the authors recognize their exclusive use of Medicare reimbursement may not represent total actual costs of care provided to patients, particularly for decedents. Finally, the authors feel their results may underestimate the growth in D:S ratios as beneficiaries with little risk in using health services may choose managed care while others are more likely to utilize more intensive health services (e.g., inpatient care).

Conclusions

Despite a legislative change that added a hospice benefit for Medicare beneficiaries in 1982, a subsequent increase in the proportion of Medicare beneficiaries receiving hospice care and home health care prior to death and a subsequent reduction in the proportion dying in acute care hospitals, this study shows evidence that the per capita utilization of costly inpatient services in the last year of life did not decrease for Medicare beneficiaries. Inpatient treatment intensity for both Medicare decedents and survivors increased between 1985 and 1999. Absolute changes in per-capita hospital expenditures, ICU admissions, and intensive inpatient procedure use were higher among decedents while relative changes were similar except for ICU admissions which grew faster among survivors. The authors suggest that net hospital expenditures for dying Medicare beneficiaries may have been even greater over the fifteen year period studied if no new hospital-based death alternatives had been introduced. Results may raise concerns over the efficiency of Medicare spending.

Formal Citation

Teno, J. M., Mor, V., Ward, N., Roy, J., Clarridge, B., J. E. Wennberg and E. S. Fisher. 2005. [Bereaved Family Member Perceptions of Quality of End-of-Life Care in U.S. Regions with High and Low Usage of Intensive Care Unit Care](#). *Journal of the American Geriatrics Society* 53(11): 1905-1911.

Subject/Category: End-of-life care quality

Key Words: Geographic variation, resource utilization

Number of References: 15

Perspective

The article is coauthored by four research physicians, two health care services researchers and a biostatistician. The authors are from Brown Medical School, Dartmouth Medical School, the University of Rochester and the University of Massachusetts. The study was funded by the Robert Wood Johnson Foundation and the National Institute of Aging.

Purpose of Article

The purpose of this article is to assess whether regional differences in medical practice intensity are associated with differences in quality of end-of-life care. The article is one of a stream of research on end of life issues.

Data

The analysis uses cross-sectional data from a retrospective mortality survey. Family members (or friends) of the decedent were identified and then interviewed via phone about the decedents' and their own experiences of the quality of end of care for the decedent using a survey instrument that assessed the quality of end-of-life care. Here, questions on the survey targeted five major domains: providing physical comfort and emotional support, promoting shared decision-making, respectful treatment of patient, attending to family needs for information and attending to family needs for emotional support. An overall assessment of the quality of end-of-life care was also created using an additive summary measure where respondents were asked to rate the quality of each of the five aspects of care on a scale of 0 (worst possible care) to 10 (best possible care). The survey targeted the highest and lowest deciles of intensive care unit (ICU) use in 25 states. Eight states were intentionally chosen as they accounted for nearly half of all U.S. deaths in 1998 with another 17 states chosen randomly. Hospital service areas (HSAs) were used as the geographic region of the local healthcare market. Deciles of usage were determined by the average number of days spent in ICUs or coronary care units (CCUs) by Medicare enrollees aged 65 and older during their last 6 months of life. These data were adjusted for age, race and sex, and obtained from the Dartmouth Atlas of Health Care. Next, deaths that occurred in these HSAs were identified. The final survey sample contained 413 and 365 decedent representatives from low-ICU-Use regions and high-ICU-Use regions, respectively. Data collected from these individuals included demographic information, process of care and decision-making information and answers to survey questions.

Methods

Usage rates of hospital and physicians services during the last six months of life for Medicare enrollees aged 65 and older residing in the sampled HSAs are presented. Differences between HSAs in the highest and lowest deciles of ICU use and measures of decedent or respondent attributes and perceptions of the quality

of end-of-life care are analyzed using a chi-square test. The Mantel-Haenszel chi-square test is used for ordered responses. Multivariate logistic regression is used to analyze whether residing in HSAs in the highest and lowest deciles of ICU use and reported perceptions of care persist controlling for demographics and decedents' medical characteristics. Due to the low number of African Americans in the HSAs, these regressions are re-run excluding African Americans but results do not differ.

Results

In comparing the intensity of medical services in the sampled HSAs, Medicare decedents from high-ICU-Use HSAs spent more than 50% more time in the hospital and three times as much time in the ICU during their final six months of life than those from low-ICU-Use HSAs. Those from higher intensity HSAs also had twice as many physician visits during their final six months. In comparing characteristics of decedents and respondents included in the final survey sample, decedents did not differ demographically between the high- and low- ICU-use regions except for race and rural residence where those in high-ICU-use regions were significantly more likely to be black and to live in non-rural areas. Over 80% of respondents in both regions were typically a close family member of the decedent and 70% had daily contact with the decedent in the last week of life. In comparing the location and processes of care reported by the respondents about the decedents' last months of life, decedents in the higher-intensity HSAs were significantly more likely to die in the ICU and to have been transferred to an institution or across institutions during their last month of life.

For the five domains measuring the quality of end-of-life care, no measure was perceived to be better in the higher-intensity HSAs. In fact, bereaved family members (or knowledgeable informants) of decedents who died in the higher-intensity HSAs reported significant insufficient help with emotional support relative to those in the lower-intensity HSAs. Residents of higher-intensity HSAs were also significantly more likely to report concerns with physician communication about decision-making and about knowing what to expect while the patient was dying. Finally, the summary rating of overall quality indicated that those in the higher-intensity HSAs were less satisfied with the quality of end-of-life care.

Limitations

The authors acknowledge several limitations. First, the follow-back design of the study utilizes family members as proxies for decedents which may have been problematic for some of the assessments such as symptom relief. Second, the cooperation rate for the study was 65% with blacks, Hispanics and younger decedents having been less likely to have a family member participate in the survey. Finally, the authors note that the observational nature of the study reflects only an association. It is certainly plausible that other attributes of higher-intensity regions may contribute to the lower quality of end-of-life care experienced by study participants in these regions.

Conclusions

Consistent with related research, this study shows evidence that higher-intensity practice patterns of medical care are not associated with an improvement in the quality of end-of-life care. Specifically, in three of the five domains of the conceptual model of patient-focused, family-centered medical care, bereaved family members (or knowledgeable informants) of decedents from higher-intensity regions reported significantly greater concerns with the quality of end-of-life care. The authors believe their findings highlight the challenges in disentangling relationships between end-of-life preferences, expectations and medical treatment utilization strategies.

Formal Citation

Wennberg, J. E., Fisher, E. S., Stukel, T. A., Skinner, J. S., S. M. Sharp and K. K. Bronner. 2004. [Use of Hospitals, Physician Visits, and Hospice Care during Last Six Months of Life among Cohorts Loyal to Highly Respected Hospitals in the United States](#). *BMJ* 328(7440): 607-611.

Subject/Category: End-of-life care resource utilization

Key Words: Resource utilization, hospital care, physician care, hospice, end-of-life care

Number of References: 20

Perspective

The article is coauthored by two research physicians, one health care economist, one statistician and two masters level research associates. The authors are from Dartmouth Medical School, Dartmouth College and the Institute for Clinical Evaluative Sciences in Toronto. The study was funded by the Robert Wood Johnson Foundation and the National Institute of Aging.

Purpose of Article

The purpose of the article is to examine the variation of utilization of healthcare resources in the last six months of life among patients of U.S. hospitals and academic medical centers that have reputations for high quality care in managing chronic illness.

Data

The analysis uses cross-sectional data from a retrospective mortality study of Medicare patients who prior to death received care from at least one of 77 hospitals that appeared in the 2001 *US News and World Report* list of “America’s best hospitals” for the treatment of heart and pulmonary disease, cancer and geriatric care. For Medicare patients who died in 1999-2000, Medicare’s hospital admission files match a decedent to the hospital used most often during the last two years of life. All utilization was included, but assigned to one hospital for summary purposes. The final study population consisted of 115,089 patients assigned to 77 hospital specific cohorts.

Methods

Utilization measures during the last six months of life and terminal care measures were generated for the 77 hospitals using patients’ Medicare claims data. These measures include: number of days spent in hospital (“hospital days”), number of days spent in intensive care units (“ICU days”), number of physician visits, percentage of patients seeing 10 or more physicians, percentage of patients enrolled in a hospice, percentage of deaths occurring in hospital and percentage of deaths involving a stay in an intensive care unit.

Hospital and physician visit rates were adjusted for age, sex, race and illness using over-dispersed Poisson regression models where the dependent variable was the total event count per decedent and the independent variables were indicator variables for the study hospitals, age (five categories), sex, race (non-black, black) and chronic condition (11 dichotomous variables for 11 chronic conditions). Over-dispersed logistic regression was used to analyze events that could occur only once (e.g., enrollment in a hospice). All covariates were centered about the population mean so that the rates reflect an average member of the study population.

Hospital specific regression coefficients were transformed into standardized rates by exponentiation and calibration so that these rates had the same overall mean as the crude hospital specific rates.

The denominator for calculating utilization rates was the full six months of observation before death. Crude hospital specific rates were calculated using the number of cohort members assigned to the hospital as the denominator (to obtain per decedent rates). Finally, variation among utilization measures was compared using coefficients of variation and interquartile and max-to-min ratios, as well as scatter plots.

Results

For the study population, 55% were female, 15% were black, just over 30% were age 85 or older, just over 40% were between ages 75 to 84, and 85% were chronically ill (many with more than one condition). The standardized utilization rates and statistical measures of variation show that intensity of care over the last six months of life and at the time of death varied substantially among the 77 hospitals. The average number of hospital days during the last six months of life was 14.5 per patient for all hospitals but was more than 27 (fewer than 10) in the highest (lowest) ranked hospital. The average ICU days ranged from 1.6 to 9.5 per patient, while the number of physician visits ranged from 17.6 to 76.2 per patient. Overall, over one-third of all patients saw 10 or more physicians in the last six months of life although this ranged from 16.9% to 58.5% across the hospitals. The percentage of deaths occurring in hospitals ranged from 15.9% to 55.6% and the percentage of deaths associated with a stay in intensive care varied from 8.4% to 36.8%. Finally, enrollment in a hospice varied among the cohorts from less than 11% of decedents to more than 43%.

When measuring intensity of care by the (unweighted) average number of hospital days per decedent, frequency of physician visits or percentage who saw 10 or more physicians during the last six months for patients loyal to major teaching hospitals located in metropolitan areas, Manhattan provided the most care followed by Los Angeles, Washington, DC and Philadelphia. Minneapolis and San Francisco had low rates on all four intensity of care measures.

Limitations

The authors acknowledge three limitations. First, with the exception of hospice care, the authors are unable to evaluate the contribution of community care services (e.g., home health agencies or nursing homes). The authors also have no information on patients' or caregivers' preferences for end-of-life care or on their satisfaction with the services provided. Second, the retrospective design of the study leads to the exclusion of patients who did not experience at least one hospital admission during their last two years of life (estimated to be 8% to 30% of deaths in 1999-2000). Hence, end-of-life hospital admission rates are based on a denominator that is too small. Finally, the authors note that they underestimate patient loyalty for medical centers that use affiliated hospitals as information on such affiliations was not always available.

Conclusions

While the authors offer that the observed variation in the utilization of end-of-life care between the sampled highly reputable U.S. medical centers may have been in part generated by substitution between hospital use, physician visits and hospice care, they argue it is more likely that a direct relation between supply (e.g., local healthcare workforce and hospital beds) and utilization of services better explains these variations. They hope future research focuses not only on how to better manage chronic illness, but how to better provide end-of-life care determined by the needs and desires of patients rather than by the capacity of the healthcare system.

Formal Citation

E. B. Lamont. 2005. [A Demographic and Prognostic Approach to Defining the End of Life](#). *Journal of Palliative Medicine* 8(Supplement 1): S12-S21.

Subject/Category: End-of-life definition

Key Words: Terminal care, medical care, patients, hospital care

Number of References: 75

Perspective

The article is written by an academic physician in the Department of Health Care Policy at Harvard Medical School who conducts research in clinical epidemiology and health services research in cancer.

Purpose of Article

The purpose of the article is to discuss how inaccurate prognostic estimates of individuals' remaining survival time has contributed to the large disparity between preferred methods of end-of-life medical care and actual end-of-life medical care treatments. The article purports this disparity may be minimized by more research focused on the prognostic accuracy of end-of-life and using this information to improve communication from physicians and to patients.

Data

The general argumentative nature of the article does not directly utilize any data. The article references abundant research based primarily on clinical studies and mortality studies.

Methods

The article addresses a set of questions on end-of-life prognostication (e.g., Why Do Health Care Providers Overestimate Survival at the End of Life?). In doing so, the article discusses reasons and solutions for the disparity between preferred and actual end-of-life medical care by citing related research results (e.g. palliative oncology research).

Results

The author provides a simple, clinical definition of end-of-life as “the time preceding natural death from a process that is unlikely to be arrested by medical care.” Despite this simple definition, the author discusses the difficulty health care providers have in prospectively recognizing the onset of the end-of-life stage. Key studies are documented showing physicians consistently overestimate patient survival. Moreover, the author reports that in the broad, clinical end-of-life arena, there exists a lack of evidence-based research to guide health care providers in making accurate prognostications, nor do there exist any reliable clinical survival algorithms. However, within palliative oncology research, a growing literature focused on identifying survival predictors of advanced cancer patients does exist. Here, multiple prospective and retrospective cohort studies have identified three broad classes of patient survival predictors: 1) patients' performance status (e.g., functional capacity measure); 2) patients' clinical signs and symptoms (e.g., lymphocyte count, white blood cell count, dyspnea, weight loss); 3) and physicians' clinical predictions (i.e., subjective assessments). The

author feels that integrating the results of this strand of research with other predictive research domains through survival models might aid physicians in prognostic estimates of end-of-life periods. For example, recent studies on terminally ill cancer patients describe integrated models that combine these broad classes of survival predictors with other prognostic variables to form a single prognostic score such as the Palliative Prognostic Index (PPI). As the author cautions however, these indices can only be used in practice if their diagnostic accuracy, such as sensitivity and specificity, meet certain acceptable thresholds. In addition, further research should determine the use of these tools for current cancer patients who are or who are not enrolled for palliative care.

The author observes there are challenges for physicians to communicate about a patient's end-of-life prognosis, as patients may have inappropriately optimistic impressions about remaining time. The author cites prior research on cancer patients that indicates such a miscommunication may lead to invasive and ineffective medical therapies rather than home-based symptom-guided care that may be more appropriate.

Limitations

The author acknowledges the inevitable challenge for end-of-life researchers in determining the time at which the end-of-life stage truly commences. For example, much research is based on patients after their referral to hospice care; however, these results may be of limited applicable value to patients who are not yet enrolled in such palliative care programs.

Conclusions

The author argues that more research focused on the development of accurate predictive survival algorithms could enable patients, families and health care providers to better recognize the onset of end-of-life. The development of these reliable predictive tools could also help remedy the systematic bias in prognostic communications between physicians and patients.

Formal Citation

Yates, J.W., B. Chalmer and F.P. McKegney. 1980. [Evaluation of Patients with Advanced Cancer Using the Karnofsky Performance Status](#). *Cancer* 45(8): 2220-2224.

Subject/Category: End-of-life patient assessment

Key Words: Survival measurement, terminal cancer, physical assessment, psychological assessment

Number of References: 6

Perspective

The article is co-authored by an oncology research physician, a research psychiatrist and a statistician.

Purpose of Article

The purpose of the article is to evaluate the reliability and construct validity of the Karnofsky Performance Status Scale (KPS), and its usefulness as a clinical tool in predicting remaining survival time.

Data

The study uses a group of advanced cancer patients, all of whom were being followed as part of the Cancer Rehabilitation Project at the Vermont Regional Cancer Center. KPS scores were assigned to patients at the time of their admission to the project. Patient demographic, physical and psychological variables were collected. Survival time was recorded for the 104 patients who died during the course of the project.

Methods

To investigate the reliability of the KPS scores, the authors first compared KPS scores obtained by social workers to those obtained by nurses for the same 52 patients within a one week period in either a clinic or hospital. The authors also compared KPS scores obtained in 50 patients' home environment by social workers to the 50 patients' scores obtained in a clinic or hospital, again within a one week period. To analyze the construct validity of the KPS scores, the authors compared 52 patients' KPS scores to variables reflecting patients' self-assessed physical and psychological well-being. Finally, for the 104 who died during the project, the authors examined the association between their KPS scores and their duration of survival from the time their scores were obtained.

Results

The authors find evidence in support of inter-rater reliability of the KPS. They report significant positive Pearson correlations between both the social workers' and nurses' KPS scores (0.69 with a p -value < 0.001), and the home and clinic KPS scores (0.66 with a p -value < 0.001). The authors find no significant difference between the average ratings obtained by social workers and those obtained by nurses. However, the authors do observe a tendency for KPS scores obtained at patients' homes to be less than scores obtained at clinical settings as the average home KPS score is over five points less than the average clinic score (with a p -value < 0.003 for a paired t -test). The authors suggest this latter result may reflect a tendency for patients' problems to seem less severe outside of their home environment, as well as a tendency for patients to overstate their well-being for clinicians.

The authors also find evidence in support of the construct validity of the KPS. Pearson correlations between patients' KPS scores and self-assessment variables related to their physical functioning are significant. The following are correlations and p -values for KPS scores and "desire for food," "sleep," "difficulty with balance," "difficulty with stairs" and "pain level," respectively: 0.40 (p -value < 0.002), 0.24 (p -value < 0.050), 0.61 (p -value < 0.001), 0.63 (p -value < 0.001) and -0.37 (p -value < 0.006). Patients' KPS scores are also correlated with some variables related to their psychological status. The following are correlations and p -values for KPS scores and "happiness," "positive affect," "negative affect," "satisfaction with life" and "overall condition," respectively: 0.12 (not significant), 0.54 (p -value < 0.001), -0.09 (not significant), 0.36 (p -value < 0.007) and 0.39 (p -value < 0.004). The authors deduce that while the KPS may be a useful indicator of patients' physical status, it may not capture variation in patients' psychological well-being beyond that already associated with patients' physical disability.

A graphical comparison of deceased patients' on-study KPS scores with the number of days prior to death shows a strong association between low KPS scores and death within a relatively short time of six months. The authors do not observe such an association between high KPS scores and a long survival time as many patients with high KPS scores subsequently die in a short period of time. The mean KPS scores for deceased patients at each of seven time points prior to death show a progressive decline from day 210 to day 60, followed by a dramatic drop in these last two months of life.

Limitations

The authors do not state any limitations to their study.

Conclusions

The authors believe their study shows evidence that the relatively simple KPS measure is reliable, valid and contains some ability to predict mortality. While this measure is primarily used on cancer patients, they suggest it may be helpful in assessing the functional status of patients with other chronic diseases.

Formal Citation

Mor, V., Laliberte, L., J.N. Morris and M. Wiemann. 1984. [The Karnofsky Performance Status Scale: An Examination of its Reliability and Validity in a Research Setting](#). *Cancer* 53(9): 2002-2007.

Subject/Category: End-of-life patient assessment

Key Words: Survival measurement, functional status measure, Karnofsky, terminal cancer

Number of References: 17

Perspective

The article is co-authored by health care services and policy researchers focused on gerontology, and an oncology research physician.

Purpose of Article

The purpose of the article is to analyze the reliability, construct validity and predictive validity of the Karnofsky Performance Status Scale (KPS).

Data

The study uses a sample of 685 terminally ill cancer patients, all of whom were part of the National Hospice Study (NHS). This sample includes only hospice patients who were admitted to a hospice between August 1, 1981 and July 31, 1982, who died by November 30, 1982, and who had a KPS score of 50 or less. Forty-seven interviewers collected information from NHS participants during an interview upon entry into the study (information used in determining KPS scores), and continued to visit patients until their death. Other detailed patient functional assessment data were obtained by hospice clinical staff upon admittance or from patients' families. Patients' primary care persons completed an overall physical QL (quality of life) assessment at the initial and each subsequent interview contact. Overall, the following three functional assessment measures were constructed for the sample and analyzed in the study: KPS scores, staff's functional assessment variables, and primary care's physical QL assessment.

Methods

All NHS interviewers had to complete an intensive orientation and training session led by a clinical team. The objective was to prepare the interviewers to consistently rate and compare NHS patients with differing performance levels. After the formal training and again after four months of field work, the 47 interviewers were asked to rate narrative examples of patients with varying KPS levels. To analyze the reliability of the interviewers' KPS scores after four months of field experience, the authors calculate Cronbach's coefficient alpha and a variant of the intra-class correlation coefficient.

To investigate the construct validity of the KPS scores, the authors compare the sample KPS measurements to two other independent sets of functional variables thought to reflect the same underlying information on patient physical performance and activity level. The authors calculate chi-square test statistics on all functional categories to test for differences in performance levels at each KPS level. The authors also compare KPS scores to pain levels and physical symptoms reported by patients, and to disease characteristics.

To analyze the predictive nature of the KPS scores, the authors perform an analysis of variance (ANOVA) with KPS as the independent variable and survival days as the dependent variable. The authors also regress the ordinal KPS score on the number of survival days. Based on the ANOVA and regression results, the authors examine the proportion of patients in three defined categories of longevity across the KPS scores.

Results

The authors find strong evidence in support of inter-rater reliability of the KPS among their non-clinician interviewers. They report significant positive inter-rater reliability coefficients for both Cronbach's coefficient alpha and the intra-class correlation coefficient (0.97 out of a maximum 1.00 with a p -value < 0.001). Based on these results, the authors believe it is feasible to utilize the KPS in other systematic research efforts.

The authors also find evidence in support of the construct validity of the KPS. Results of chi-square tests on functional activities of daily living imply that differences in performance for each KPS level are significant (p -value < 0.001). Here, the proportion of patients able to function independently increases for higher levels of KPS. For lower levels of KPS, the proportion of patients unable to perform these activities with or without assistance increases dramatically. Similar significant results (p -value < 0.001) are observed when examining the severity index (created from responses to the functional activities) for patients at each KPS level and the physical QL at each KPS level. Hence, both interviewers and patients' primary care persons appear to evaluate patients consistently with respect to physical dimensions of performance status which supports the view that the KPS is a reliable measure of functional status. The authors find no significant relationships between KPS scores and pain levels, physical symptoms reported by patients or disease characteristics.

The authors observe a strong association between low KPS scores and death within a relatively short period of several months. Results of ANOVA show a significant, direct monotonic relationship between KPS and survival time (p -value < 0.001). KPS explains nine percent of the variance in survival time. The regression analysis suggests an increase in one KPS level (e.g., 20 to 30) yields an increase of approximately 15 days of survival. The skewed longevity distributions for each KPS level lead to a higher proportion of prediction errors in the direction of longer lives. Analysis of KPS levels across three constructed patient longevity categories shows the majority of patients with low KPS levels die within 18 days of hospice admission while over 70% with KPS level 50 live beyond 36 days. The authors argue that based on these results the predictive validity of KPS is confirmed with regards to a sample of terminal cancer patients.

Limitations

The authors acknowledge the absence of patients in their sample in the upper ranges of the KPS which may be the result of their sample constraints. They suggest this absence may explain the lack of evidence of a positive association between reported symptoms and KPS, as symptoms may be more relevant to physical performance for less debilitated terminal patients.

Conclusions

The authors believe their analysis demonstrates the KPS measure as reliable, constructively valid and capable of predicting mortality in terminally ill cancer patients. Further, they feel the most effective application of the KPS is as a stratifying measure in research, especially in clinical trials where patient survival constitutes an outcome of interest. The KPS could also serve as a study eligibility criterion when applied by trained professionals.

Formal Citation

Rosenthal, M. A., GebSKI, V. J., R. F. Kefford and R. C. Stuart-Harris. 1993. [Prediction of Life-Expectancy in Hospice Patients: Identification of Novel Prognostic Factors](#). *Palliative Medicine* 7(3): 199-204.

Subject/Category: End-of-life patient assessment

Key Words: Hospice, life expectancy, prognosis, survival measurement

Number of References: 12

Perspective

The article is co-authored by medical oncology and palliative care research physicians and a biostatistician.

Purpose of Article

The purpose of the article is to analyze the predictive significance of proposed objective clinical factors on the survival duration of terminally ill patients.

Data

The prospective study uses a sample of 148 patients at first admission to one of two Australian hospices between June 1989 and September 1990. Two physicians (two of the co-authors) were responsible for all admissions at both hospices. After a full medical interview and physical examination of each patient, data were collected prospectively on nineteen clinical factors selected on the basis of previous studies, clinical impressions of medical staff and utility in a hospice setting. These factors include: presence of cardiac failure or mental confusion, pulse rate, respiratory rate, temperature, blood pressure, Eastern Cooperative Oncology Group (ECOG) performance status (PS), number of metastatic sites, previous treatments, use of morphine, more than five kilograms of weight loss in the previous month, admission to hospice at first referral to palliative care service and laboratory test outcomes for various ailments (e.g., anemia, hypercalcaemia). The patients' dates of initial diagnosis, hospice admission and death were also recorded.

Methods

Ordinal regression analysis examined the relationship between the nineteen clinical factors and five established groups of survival duration. Patients' survival times were estimated from the date of hospice admission to the date of death. These times were categorized into five ordered groups: less than one week, one to four weeks, one to three months, three to six months and more than six months. No censored observations were observed. In addition, time from initial diagnosis to date of hospice admission was also recorded.

Patients' resulting clinical factors were classified as either normal or abnormal. For example, a pulse rate outside of sixty to one-hundred beats per minute was defined as abnormal. Laboratory test outcome values (e.g., serum calcium) were also classified as normal or abnormal based on the normal values from the Departments of Clinical Chemistry and Haematology of Westmead Hospital. Patients' ECOG performance status was classified into one of two groups, 'good' (PS = 0-2) or 'poor' (PS = 3-4).

Results

The authors report four factors measured at the time of hospice admission as significantly associated with shortened survival duration. The four factors along with their regression p -values (in parenthesis) are: poor ECOG performance status (0.002), admission to hospice at first referral to palliative care service (0.007), elevated serum bilirubin (0.011), and low systolic blood pressure (0.049). These results differ from findings of other studies where variables such as weight loss, tumor type or the number of metastatic sites are significantly related to shortened survival of patients.

The authors further apply the sixteen combinations of these four significant variables to their ordinal model to predict the probability of a patient being categorized into each of the survival groups. For each combination, the category with the highest probability is reported and tends to be approximately fifty percent. For all of the combinations, the most likely outcomes are survival of less than one week (four combinations), one to four weeks (five combinations) or one to three months (seven combinations).

Limitations

The authors do not state any limitations regarding their study.

Conclusions

The authors believe that while their study confirms ECOG performance status as an important predictor of survival, the other three significant prognostic variables and the lack of significance of other clinical factors is surprising. This emphasizes the difficulty in predicting life-expectancy of patients with incurable diseases. Ultimately, the authors wish to construct a simple bedside scoring system to better predict the survival of cancer patients. However, in order to do so, the authors feel further research is necessary including validation of their work by themselves as well as other researchers.

Formal Citation

Anderson, F., Downing, G. M., Hill, J., L. Casorso and N. Lerch. 1996. [Palliative Performance Scale \(PPS\): A New Tool](#). *Journal of Palliative Care* 12(1): 5-11.

Subject/Category: End-of-life patient assessment

Key Words: Functional status measure, palliative care, Karnofsky

Number of References: 31

Perspective

The article is co-authored with three authors from the Victoria Hospice Society, one of whom is a Medical Director of Research, and two authors from a nursing care facility, one of whom is a nurse in Victoria, British Columbia.

Purpose of Article

The purpose of the article is to share an application of a new tool for measuring performance of patients using palliative care.

Data

The study collected primary data from an organization with eight home nursing care offices that serve Victoria and the surrounding region. Data from a one-year period were collected and summarized using the PPS tool. On average, the offices serve 150 patients at any one point in time. There are 600 deaths per year, with one-half being home deaths. Home care nurses record the PPS rating on all palliative patients after each home visit that may occur biweekly to daily depending on the needs of the patient, as well as recording the amount of direct and indirect nursing care time spent at each visit. For patients needing acute care, the PPS is completed both upon admission and discharge.

Methods

A new tool, called the Palliative Performance Scale (PPS), was developed as an enhancement of the Karnofsky Performance Scale (KPS). The KPS was developed in 1948 to assess the functional performance of cancer patients. The new PPS tool provides a way to measure a progression of decline in patients utilizing palliative care. For the PPS, performance is separated into 11 levels, measured in 10% decrements from fully ambulatory and healthy (100%) to dead (0%). The scale contains five factors to distinguish the levels: (a) ambulation; (b) activity and evidence of disease; (c) self-care; (d) intake; and (e) conscious level. Decisions on level are progressive, proceeding by category from (a) to (e).

Results

A snapshot for a particular day of 119 palliative care visits shows that a majority of the patients were in the 40 to 70% range, with less than 20% of the patients with a PPS score of 30% or below. Most of the nursing hours are spent with patients in the PPS mid-range, with fewer hours for those above the 70% PPS score and more hours for those with low PPS scores.

For those patients admitted to an acute facility, most have PPS scores between 30 to 50%, with over 50% of the patients dying. Those with the lowest scores at admission had the shortest number of days until death. For example, for those admitted with a PPS score of 10%, all died in the unit with an average stay of 1.88 days. For those admitted with a PPS score of 50%, 37% died. For those who died, their average stay was 13.87 days. For those who were discharged from the unit, their length of stay was longest for those with lower PPS scores, and generally decreased with higher PPS scores.

Limitations

No perceived limitations. Need for future research to determine relationship and usefulness with other instruments, as well as gather more data for future studies.

Conclusions

The PPS tool provides an update to the KPS tool for assessing cancer patients and facilitating communication between providers, patients, and family members. The PPS tool allows nurses and hospitals to use the instrument as a workload measurement tool.

Formal Citation

Barnato, A. E., Anthony, D. L., Skinner, J., P. M. Gallagher and E. S. Fisher. 2009. [Racial and Ethnic Differences in Preferences for End-of-Life Treatment](#). *Journal of General Internal Medicine* 24(6): 695-701.

Subject/Category: End-of-life preferences

Key Words: Race, ethnicity, terminal care, Medicare

Number of References: 47

Perspective: The article is co-authored by two research physicians, two sociologists and a health economist.

Purpose of Article

The purpose of the article is to describe racial and ethnic differences in preferences for end-of-life medical treatments controlling for sociocultural co-variables thought to impact choice and use of healthcare services.

Data

The article utilizes a national sample of Medicare beneficiaries who were age 65 or older as of July 1, 2003. The beneficiaries must be alive and eligible for either Part A or Part B of Medicare between July 1, 2003 and June 30, 2004, and residents of a U.S. Hospital Referral Region in 2003 and 2004. From this national sample, a simple random sample of 4,000 beneficiaries is drawn, as well as a simple random over-sample of 700 blacks. Ultimately, 2,847 of 4,610 potentially eligible beneficiaries (90 were ineligible) responded to the authors' survey instrument by either phone (55%) or mail (45%). Of the 2,847 respondents, 2,810 self-reported into the following mutually exclusive groups: 75% non-Hispanic whites, 17% blacks, 4% Hispanics and 4% "other."

Methods

The authors designed a set of survey questions to investigate beneficiaries' concerns and preferences for end-of-life care in the last year of life in the event of a terminal illness. The survey also collected respondents' information on socio-demographic variables, health status, social networks, and perceptions of quality and access to health care. Responses to five survey questions create seven dichotomous dependent variables. Two relate to medical treatment concerns (e.g., receiving too little or too much medical treatment in the last year of life) and five relate to medical care preferences (e.g., want mechanical ventilation to prolong life). Another aggregate dependent variable is created by summing the responses to the survey questions. The authors then apply ordinary least-squares regression, multivariate logistic regression, and multivariate ordinal logistic regression on these various dependent variables treating race as primary independent variables while controlling for other variables thought to effect the relationship between end-of-life treatment preferences and race (e.g., age, education, financial strain, living arrangements, self-assessed health status or the use of a personal physician).

Results

Different races reflect different characteristics thought to influence health care utilization. For example, non-white minorities report a lower level of education and more financial strain when deciding whether or not to obtain medical care. These groups are less likely to have a personal doctor, have lower confidence in their

abilities to manage their health conditions and are more likely to feel they received an insufficient amount of medical care in the prior year. Interestingly, the non-white minorities reflect an overly-optimistic view of the recovery effectiveness of mechanical ventilation.

While the majority of respondents, regardless of race, prefer to die at home in the event of a terminal illness and prefer not to receive life-prolonging drugs with uncomfortable side effects or mechanical ventilation, the minority groups are more likely to favor intensive treatment options near death. More blacks and Hispanics than whites wish to spend their final days in a hospital room, want potentially life-prolonging drugs with uncomfortable side effects, and want mechanical ventilation for life extension. Fewer blacks and Hispanics than whites want potentially life-shortening palliative drugs. The authors' multivariate analyses suggest sociodemographic variables such as gender and education, a desire for specialists, and an overly-optimistic belief in the effectiveness of mechanical ventilation explain some of the preferences for life-sustaining drugs and mechanical ventilation among the minority races.

Limitations

The authors acknowledge the following limitations of the survey: a reliance on a hypothetical scenario, item-non-responses, the lack of a measure of trust in the health-care system and intentionally over-simplified end-of-life preference questions.

Conclusions

Similar to other studies based on local or regional samples, this study of a national sample of Medicare beneficiaries that controls for demographic and sociocultural variation finds that racial minorities anticipate a stronger preference toward more aggressive medical treatments near death. The authors do caution that these results should not be interpreted as generalizations as any end-of-life treatment decision should be customized to individual preferences.

Formal Citation

Malhotra, C., Chan, A., Do, Y. K., R. Malhotra and C. Goh. 2012. [Good End-of-Life Care: Perspectives of Middle-Aged and Older Singaporeans](#). *Journal of Pain and Symptom Management* 44(2): 252-263.

Subject/Category: End-of-life preferences, Singapore

Key Words: Older adults, end-of-life, advance care planning, place of death, religion, cost, communication, palliative care

Number of References: 56

Perspective

The article is coauthored by three public health researchers with backgrounds in medicine, a sociologist and a palliative care clinician; all associated with the Program in Health Services and Systems Research at Duke-National University of Singapore Graduate Medical School in Singapore. The project was funded by the Lien Centre for Palliative Care.

Purpose of Article

The purpose of the article is to identify the key components of good end-of-life care as perceived by middle-aged and older Singaporeans (50 years or older).

Data

The qualitative study utilizes transcribed results of focus groups (described below) to summarize preferences regarding end-of-life care. Demographic data on the participants were also collected. Slightly less than half the focus group participants were older than 69, about 46% were women, 64% were married, 60% were Chinese, 30% were Christians and 21% were Muslim.

Methods

The study used a purposive sample, one where participants are chosen because of some characteristic and were chosen through snow-balling (people who know people who know others). Sixty-three Singaporeans were placed into nine different focus groups of size five to eight that were stratified by age (50-69 years and 70 years and older) and ethnicity (Chinese, Malays and Indians). For the Chinese, separate focus groups were conducted for Chinese Christians and Chinese non-Christians (Buddhists and Taoists). Each focus group session lasted 60-90 minutes where a trained facilitator used a semi-structured interview guide developed by the authors. Each participant was asked whether they thought it was important to plan for the end of life, what they thought of when they planned for their end of life and eight questions regarding preferences for end-of-life care. Thematic analysis was conducted on the transcribed results of these focus groups to identify and report themes.

Results

Eight components of good end-of-life care were identified by the Singaporean representative focus groups. First, participants were concerned about receiving physical comfort at the end of life where pain and suffering should be minimized. Second, participants wished to avoid any inappropriate prolongation of the dying

process where their physical and psychological suffering might be extended. Third, there was a desire to receive medical care and treatment at the end-of-life that was sensitive toward their religious and spiritual beliefs. Fourth, participants wished to avoid burdening their families both emotionally and financially with issues related to end-of-life care. Fifth, participants were concerned about the financial implications of end-of-life treatments and expressed a desire to avoid expensive care. Sixth, there was a desire to be cared for by a single, trustworthy doctor who was empathetic and communicative. Seventh, most participants wished to maintain control over care and treatment decisions so long as they were capable of doing so. Finally, participants expressed a desire to achieve a sense of completion at the end of their lives in that they had performed duties toward their families and society.

Limitations

The authors acknowledge that although the main strength of their study is representation from the three main ethnic groups in Singapore (Chinese, Malays and Indians) as well as the main religions, the preferences of the general Singaporean population regarding end-of-life care could be different from those of terminally ill patients or their bereaved relatives.

Conclusions

Singapore is a multiethnic society and one of the most rapidly aging countries in Southeast Asia. However, little was known about what kind of care Singaporeans prefer at the end of life. This study identified eight components of good end-of-life care involving the person, family and health services. As a result, a focus on better management of pain, training of caregivers and doctors, shared decision making and availability of affordable care may improve care at the end of life for Singaporeans in the future.

Formal Citation

Perry, J. E., L. R. Churchill and H. S. Kirshner. 2005. [The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives](#). *Annals of Internal Medicine* 143(10): 744-748.

Subject/Category: Ethics and legal aspects of patient care

Key Words: Health care decision-making, persistent vegetative state

Number of References: 26

Perspective

The article is co-authored by a lawyer, an ethicist, and a clinician.

Purpose of Article

The purpose of the article is to articulate the stream of events leading to the death of Terri Schiavo in 2005 and summarize the legal, ethical and medical treatment of patients in a persistent vegetative state.

Data

The opinion-oriented nature of the article does not directly utilize any data.

Methods

The article is a case study regarding the events leading to the death of Terri Schiavo.

Results

In February 1990, Terri Schiavo collapsed and her brain was deprived of oxygen for several minutes. At the end of that year, she was diagnosed to be in a persistent vegetative state, as described in Table 1 of the paper.

From a legal point of view, the case fell in the state legal system. Legally, two issues needed to be resolved: what was Terri Schiavo's medical condition and what would be her choice as to directed medical care. This was resolved by the medical findings confirming her persistent vegetation state, as well as statements made by her husband that she would have not wanted to stay alive.

From an ethical point of view, the issue was of respect for autonomy, or the freedom of will. This framework of self-determination was felt to dominate other points of view such as medical goodwill, sanctity of life or quality of life.

Limitations

None

Conclusion

The article is a perspective piece that examines the Terri Schiavo case from medical, legal and ethical points of view and concludes that the appropriate actions were taken in each realm.

Formal Citation

Raphael, C., J. Ahrens, and N. Fowler. 2001. [Financing End-of-Life Care in the USA](#). *Journal of the Royal Society of Medicine* 94(9): 458-461.

Subject/Category: Financing

Key Words: Financing, Medicare, hospice care, cost, access

Number of References: 16

Perspective

The article is co-authored by two health care administrators of a nonprofit home health care organization and a research project manager who specializes in home care policy and research.

Purpose of Article

The purpose of the article is to provide an overview of how end-of-life care is funded and accessed in the U.S., as well as suggest improvements given projected population trends and current system limitations.

Data

The factual and opinion-oriented nature of the article does not directly utilize any data. The article references related research based primarily on macro-level studies and projected trends. While many of these studies are based on data that is over fifteen years old (indeed, the article itself is over twelve years old), the projected trends and the authors' suggestions remain relevant.

Methods

The article first describes current financing of end-of-life care, trends affecting end-of-life care, and barriers to access and financing. The article then offers micro and macro level changes with a focus on hospice care.

Results

In the U.S., end-of-life health care expenditures are typically financed by a combination of federal spending (Medicare), state spending (Medicaid), private insurance companies, individuals and their families in the form of caregiving. Medicare plays a significant role in end-of-life care as evidenced by the large percentage of decedents who are Medicare beneficiaries at the time of their death and by the relatively stable 25 percent of annual Medicare payments attributable to patients in their last year of life. (This 25 percent remains true today; see Riley and Lubitz (2010).) According to a 1999 article, Medicare costs for beneficiaries indicate that end-of-life costs vary based on the site of death as hospitals tend to be almost twice as expensive as other locations, such as one's home. Hospice care is another option for end-of-life care that may provide an experience closer to patients' needs and preferences, and is often covered by Medicare's hospice benefit. Throughout the 1990s, hospice use and the number of hospices increased although hospice revenues and profit margins dropped due to the short-term stay of patients. It is unresolved if hospice care is less expensive relative to other forms of end-of-life care.

The provision and financing of end-of-life care is changing due to an aging population (over 72 million aged 65 or older by 2050), increasing diversity (Latino population growth), and changing patterns of death and

disability (four of top five leading causes of death are chronic conditions). These statistics are from the 2000 U.S. Census Bureau and a 2000 report to the Medicare Payment Advisory Commission.

The authors feel there exist significant barriers to finance and access end-of-life care starting with individuals simply being uninformed about their end-of-life care options. Financial barriers stem from the inappropriate coverage design of most insurance plans (including Medicare) that focus on inpatient hospital care rather than palliative or custodial care that is necessary for quality end-of-life treatments. Access barriers stem from the lack of awareness of the Medicare hospice benefit, acceptance of the hospice benefit given cultural and language issues, acceptance of the Medicare hospice benefit in lieu of the regular Medicare benefit, and ability to supplement the hospice benefit with other caregivers. These access barriers are exemplified by the underutilization of hospice care by groups such as low income populations, minorities, nursing-home patients, and patients with non-cancer diagnoses such as the HIV/AIDS population.

The authors offer several improvements to how end-of-life care is financed. Their suggestions build on the strength that hospice care is a standard benefit included in the Medicare program and in many commercial insurance plans, but limited knowledge about and access to hospice currently prevents patients from taking advantage of these options. Incremental changes to end-of-life financing include developing a payment adjuster for high-cost hospice benefit patients, increasing the cultural diversity of hospices, modifying the hospice benefit to include the needs of non-cancer patients, and providing financial incentives for hospitals and nursing homes to provide quality end-of-life care. More comprehensive systematic changes to end-of-life financing include strengthening financial emphasis on supporting family caregiving, changing the flow of payments to encourage continuity of end-of-life care across sites and time, and providing end-of-life care based on disease severity and functional disability, rather than prognosis. The authors believe these changes would allow appropriate palliative care, such as hospice care, to be available to anyone with a progressive chronic illness much earlier in the disease trajectory rather than to the dying who are in the last weeks of life.

Limitations

None mentioned.

Conclusions

The authors believe the current U.S. system of end-of-life care contains flaws in how it is financed and accessed. As the aging U.S. population grows and becomes more culturally diverse, changes in financing and access are necessary so that good end-of-life care is the norm rather than the exception. The new system should clearly define and measure essential elements for quality end-of-life care, support patient and family preferences, and provide them with knowledge of their options so they can make optimal, informed decisions about end-of-life care.

Formal Citation

Cook, K., D. Dranove and A. Sfekas. 2010. [Does Major Illness Cause Financial Catastrophe?](#) *Health Services Research* 45(2): 418-436.

Subject/Category: Financing

Key Words: Uninsured, costs of illness, health insurance coverage, median (quantile) regression, causal inference, matching, medical bankruptcy

Number of References: 17

Perspective

The article is co-authored by a Ph.D. candidate in economics (lead author) and two economics professors, all from the Kellogg School of Management at Northwestern University.

Purpose of Article

The purpose of this article is to examine the impact of a new major illness on financial assets for the near-elderly, and study how that impact is affected by health insurance.

Data

The article uses the first eight waves of the Health and Retirement Study (HRS), a longitudinal study of the near-elderly and elderly administered by the Institute for Social Research at the University of Michigan. The study began in 1992 with a cohort of noninstitutionalized Americans born between 1931 and 1941, and their spouses. Additional six-year cohorts were added in 1998 and 2004. Participating households are interviewed every two years from entry until death. The authors utilize the RAND HRS version of the data. Data are limited to households with at least one member under 65 as nearly all individuals over 65 have Medicare and are thus not suitable for the study. Households with no financial respondent, extremely high assets (\$3 million) or income (\$400,000), zero or negative net worth, or important missing data are also excluded. The final full sample includes 454 newly ill, uninsured households, 3,175 newly ill, insured households, 3,810 healthy, uninsured households and 22,197 healthy, insured households. All financial variables are scaled to constant year 2006 dollars using the Consumer Price Index.

Methods

The authors identify respondents who have a new major illness, defined as the presence of diabetes, cancer, lung disease, heart disease, stroke, or psychiatric problems not reported in the prior biannual survey. Newly ill respondents are categorized based on whether they were insured at the time of that prior survey. Newly ill, uninsured participants are then exactly matched with participants in the other groups based on assets, income, pre-illness home ownership, presence of an existing medical condition, the type of new illness (for the newly ill), number of other new diagnoses, existence of prior conditions (for the newly ill) and marital status to account for differences in wealth and income. Difference-in-difference (DD) median regressions are used to compare the change in assets of the newly ill, uninsured group with the change in assets of the newly ill, insured group. Triple difference (3D) median regressions are used to compare the change in assets of the newly ill, uninsured group with the change in assets of each of the other three groups while controlling for the potential differences in wealth trajectories across the groups. Median regression was chosen rather than

Ordinary Least Squares as the median is a better measure with highly skewed data such as income and wealth. Wealth includes all household assets except the value of the primary home.

Results

Controlling for overall trends in wealth in each group via the 3D median regressions, the median absolute loss in assets for a newly ill, uninsured household is an additional \$4,240 relative to the median loss for a newly ill, insured household. The additional percentage loss in wealth, again relative to insured households, is 53.8% for a newly ill, uninsured household. This indicates that uninsured households are vulnerable to serious declines in wealth at the incurrence of one major illness.

Limitations

The authors note two limitations. First, they caution that their analysis does not include a representative sample of insured households as these households have finances similar to uninsured households. They have relatively low assets and income and are more likely than others in their age cohort to have group health insurance rather than individual health insurance. Hence, conclusions drawn from this study should be limited to those relative to uninsured households. Second, for both insured and uninsured households, the effect of illness is measured at most two years after its onset. The financial damage may persist for much longer and is not reflected in the results of this study.

Conclusions

The results indicate that the median near-elderly household with a newly ill, uninsured member substantially depletes its accumulated assets while controlling for financial changes that occur among the healthy uninsured and the newly ill insured. In short, such a household is one major illness away from financial catastrophe that could result in delayed retirement or a lower standard of living during retirement. Compared with the uninsured, matched insured households suffer no measurable loss of assets upon falling ill. This indicates that the current insurance system does provide a financial safety net for its customers.

Formal Citation

Crippen, D., and A. E. Barnato. 2011. [The Ethical Implications of Health Spending: Death and Other Expensive Conditions](#). *Journal of Law, Medicine & Ethics* 39(2): 121-129.

Subject/Category: Financing, ethics

Key Words: Financing, cost, life-cycle, resource allocation, generational transfer

Number of References: 7

Perspective

The article is co-authored by a public finance advisor, who served as Director of the Congressional Budget Office, and a physician who was a visiting scholar at the Congressional Budget Office.

Purpose of Article

The purpose of the article, an opinion-piece, is to consider “end-of-life” care and expenses as a stage in an individual’s life-cycle so its costs and financing mechanisms may be compared to the costs and financing of other life-cycle stages. The article also highlights the downside of pushing the growing financial burden of health care consumption onto future generations.

Data

The factual and opinion-oriented nature of the article does not directly utilize any data. The article references related research based on macro-level studies, reports, expert opinions and projected trends.

Methods

The article first describes how health care costs are financed within and across generations in a developed, modern economy. After some discussion on the reasons for increasing health care cost and health care reform, the authors present several suggestions for reducing health care costs so that the growing debt obligation left for future generations can be minimized.

Results

In economically developed countries, an inter- and intra-generational relationship is maintained through personal responsibility to family and the reallocation of goods and services. Cross-sectional transfers from working adults (via taxes) are directed towards the elderly (e.g. health care and social security) and towards children (e.g. education and Medicaid). A major factor is the size of the elderly versus child populations as to how monies are allocated. Across a current population, total consumption of resources created and transferred is essentially a zero-sum game as the more one group consumes, the less there is for other groups to consume. In the U.S., much more is spent on health care for the elderly than on education and safety-net health care for children, where most of the funding for both groups comes from the taxation of working adults. Taxation for health care occurs more at the federal level through Medicare and Medicaid, while taxation for education occurs at the state or municipal level. The authors feel that this current public allocation of resources between the young, the working and the elderly is not necessarily wrong or unethical. However, they argue that if the high cost of health care could be reduced, this would allow resources to be

used for the young or other segments of society. Finally, the transfer of resources across generations can be altered in ways that affect future generations positively if national savings increases, or negatively if borrowing occurs (by any sector or the government) to fund current consumption. Under existing U.S. health care policies, the present generation of children will be expected to pay not only for their own children and parents, but also for past generations.

While end-of-life spending contributes significantly to U.S. health care costs, the authors argue the overall increasing cost of health care is primarily due to increase in chronic disease, associated technology and costs of treating individuals with multiple chronic conditions. Further, those with chronic disease are not just the elderly as behavioral health issues tend to be associated with chronic disease (e.g. obesity and diabetes) and related to income-level. The authors believe better health information systems are needed to coordinate care across providers and service settings, but more importantly incentives should be developed for providers to learn how to efficiently treat multiple conditions in one patient. Moreover, the primary objective of recent health reform legislation focuses on the expansion of coverage and financing of health care for previously uninsured citizens. This reform may come at a substantial cost that can add to increasing health care costs, unless it is financed appropriately, or other changes are enacted to help suppress future cost increases.

Much of the large disparity between resources consumed by today's youth relative to today's elderly stems from amounts spent on elderly health care. This disparity in consumption will grow over the future and cause more debt to be accumulated. For example, with current laws, in less than 20 years, Social Security, Medicare and Medicaid will require funding levels near the entirety of what we currently collect in federal revenues. Both the continuation of these existing large deficits and growth of "new" deficits through current health care reforms and increasing chronic disease treatment costs will leave a tremendous debt obligation for future generations. These obligations must ultimately be addressed by significant tax increases, cuts in other programs or, most likely, continued unprecedented borrowing. Hence, to the extent this latter strategy is used, many future generations will pay for the current baby boomers' retirement, not just the boomers' children as the basic social compact would suggest. The ethics of this behavior are brought into question by the authors.

Limitations

The authors caution that some projections are based on assumptions such as current tax rates.

Conclusions

The cost of health care in the U.S. has significant generational implications whether analyzed at one point in time or over many years. Health care plays a major role in determining the allocation of resources across our current population and the practice of borrowing from future generations to fund current consumption. The ongoing health care of patients with multiple chronic conditions poses another challenge in resolving both inter- and intra-generational problems associated with health care costs. The authors believe it is possible to reduce health care costs by giving patients' with chronic disease better health and developing a national research agenda to better understand the interactions of chronic conditions and their treatment. In doing so, they feel we can limit the ethically questionable practice of financing today's spending on health care by borrowing from future generations.

Formal Citation

Artnak, K. E., R. M. McGraw and V. F. Stanley. 2011. [Health Care Accessibility for Chronic Illness Management and End-of-Life Care: A View from Rural America](#). *Journal of Law, Medicine & Ethics* 39(2): 140-155.

Subject/Category: Health care access

Key Words: Accessibility, rural areas, disease management, chronic illnesses, health care expenditures

Number of References: 100

Perspective: The article is co-authored by a practicing clinical psychologist, an academic nurse and a physician.

Purpose of Article

The purpose of the article is to describe the unique challenges of providing quality and affordable end-of-life care in rural areas compared to urban settings. The article offers several approaches to improving the delivery of health care in rural communities.

Data

The descriptive nature of the article does not directly utilize any data. The article references research based on macro-level studies and surveys, population and cost trends in both urban and rural areas, proposed and enacted legislation, and opinions from health care institutions and organizations.

Methods

The article first describes the challenging landscape that exists for delivery of quality end-of-life care and chronic disease management in the United States. Challenges are then analyzed from a rural perspective with the assistance of vignettes that illustrate several inherent obstacles found in a rural setting. The authors conclude by providing suggestions on how rural communities can improve their access to quality health care.

Results

To better comprehend the challenges rural areas face in maintaining quality and affordable health care, the authors first describe factors they believe limit the efficient provision of quality health care in any environment. These factors are the nature of chronic illness, the access to and cost of health care services, and the level of communication between and among providers, patients and families. As the baby boomer generation becomes elderly, its members will likely contract multiple chronic conditions which will require abundant, costly health care services. Access to care will continue to be paramount in treating chronic illness. Despite large expenditures on chronic illness, the authors report data showing no correlation between amounts spent on or intensity of health care services and quality outcomes for patients with chronic diseases. The authors argue that as our health care system becomes more complex (e.g., medical subspecialties), better communication will be needed to better coordinate treatment plans for those with chronic illnesses. However, the authors feel communication has been quite poor as evidenced by the general misunderstanding of chronic illness that requires care rather than unlikely cures. The coordination of care for individuals with multiple chronic conditions is also often limited due to restrictive provider reimbursement policies.

Overcoming these difficulties is challenging in any setting, but these factors tend to be magnified in a rural setting where accessibility to health care is more constrained due to the characteristics of the community.

The authors propose that geographic isolation (i.e., distance), lower incomes, ethnic diversity, poverty, a disproportionate number of working-age citizens (including health care professionals), a significant elderly population and poor communication all contribute negatively to rural health care. Distance is the main characteristic in limiting the quantity, quality and affordability of health care in rural areas. It increases time spent by patients and providers in accessing one another. It adds costs to necessary transportation as any particular health care service or medical supply may be hundreds of miles away. For elderly patients seeking chronic illness care, this time and distance hurdle can be both dangerous and exhausting. Hence, the existence of residential care (e.g., nursing homes) in rural areas provides a critical alternative to those with chronic illness who can no longer live at home or incur the costs of travel in seeking care. Hospice care is rare in rural communities because patients require physician certification and physician availability is often limited in rural areas. Indeed, distance – both geographic and mental – plays a role in attracting and keeping health care professionals in rural areas. Urban areas simply tend to possess more desirable health care career characteristics such as technology, education, professional peers and higher paying employment opportunities. Finally, the authors claim that certain demographics of rural communities such as lower education and income levels, minority populations, and diverse cultures, create an environment where poor or miscommunication regarding end-of-life care options can occur due in part to a lack of trust of “outsiders” especially when discussions occur away from home communities.

To improve the delivery and quality of health care in rural communities, the authors believe health care must become more integrated. They suggest any rural health care reform strategies include increasing available human capital devoted to the rural healthcare workforce (including payment of family caregivers), improving the quality and permanency of professional healthcare workers through creative recruiting and retention efforts (e.g., targeting physicians near retirement, investing in technology infrastructure and telemedicine), and overcoming cultural barriers of mistrust so that rural families can participate in end-of-life planning and decision making with providers. Meaningful discussions about treatments, outcomes, risks and costs can only occur with informed communications between patients and providers who have earned the trust of their patients.

Limitations

The authors acknowledge that their recommendations for improving the provision of health care in rural communities are contingent upon the collaboration and cooperation of regulators, health care providers, patients, families and the rural communities themselves.

Conclusions

Many of the problems associated with the American health care system are magnified in rural communities. The authors believe that reasonable approaches to solving these problems do exist, and will involve an integrated, cooperative effort by all stakeholders. A cornerstone of the authors’ proposed solutions is improved communication between and among providers, patients and families. In rural areas this is especially challenging due to the shortage of health care professionals, the distance that must be traveled within communities and the lack of trust between residents and outsiders. However, the authors feel a better dialogue will increase the understanding of the nature of chronic illnesses and increase informed participation of chronic patients in the decision making regarding their treatment plans.

Formal Citation

P. B. Bach. [When Care Is Worth It, Even if End Is Death](#). *New York Times*. 12 December 2011.

Subject/Category: Healthcare spending, ethics

Key Words: Spending, policy, intensive care, healthcare metrics

Number of References: 0 citations included

Perspective

The author is a research physician who serves as the director of the Center for Health Policy and Outcomes at Memorial Sloan-Kettering Cancer Center in New York and was a senior advisor at the Centers for Medicare and Medicaid Services.

Purpose of Article

The purpose of the article is to discuss the inaccuracies created by solely relying on healthcare data from patients who die after intensive treatments.

Data

The narrative nature of the article does not directly utilize any data, but does reference aggregate statistics on healthcare spending as well as other published academic studies.

Methods

The article uses a real case experience of a patient with a dire prognosis as an example of when intensive, critical medical care is worthwhile. This case serves as an introduction into a broader discussion of the inappropriateness of using data from only those patients who are not saved.

Results

Early in his medical career, the author treated a patient with a large blood clot in his intestine. The patient's heart was convulsing, and bacteria from his gut would soon lead to a fatal infection. Nevertheless, he was taken to the intensive care unit (ICU) and, fortunately, saved. Seven of eight patients with the same diagnosis survive, meaning that on average one in eight die. All eight spend extremely expensive time in the operating room and ICU. The author asks whether the dollars spent on that eighth patient, who is not saved, are really wasted as inferred by some researchers. The answer, he argues, is no. It is impossible for the physician to know which seven patients will live, so all eight should be treated equitably in that they receive the same intensive, expensive critical care. The author acknowledges that some medical treatments are expensive and do little to improve the probability of a patient's survival or alleviate pain. These treatments should rightly be avoided. The author also points out that, in general, sicker patients tend to require more expensive care and are also more likely to die. Some medical ranking systems of hospitals and states however, focus only on money spent on patients that eventually die punishing those who spend more. More careful studies show that institutions that spend more on caring for the sick have better health outcomes than those that spend less.

Limitations

None

Conclusion

The author disputes the notion that all money spent on patients who are not saved is wasted. He feels we must develop a more rational calculus of the worthiness and effectiveness of treatments, doctors, and hospitals. Simply summing the cost of caring for patients who die fails to consider the uncertainty doctors face when providing care and negates the value of palliative care. The evaluation of an individual patient's care plan should consider cost and probability of health improvement. This may lead to a discussion of whether to administer, for example, extremely expensive treatments to a patient with terminal cancer and a low probability of recovering. Unfortunately, he believes such a discussion at a societal level is currently not possible.

Formal Citation

Taylor Jr., D. H., Ostermann, J., Van Houtven, C. H., J. A. Tulsky and K. Steinhauser. 2007. [What Length of Hospice Use Maximizes Reduction in Medical Expenditures Near Death in the US Medicare Program?](#) *Journal of Social Science & Medicine* 65(7): 1466-1478.

Subject/Category: Hospice care

Key Words: Hospice, cost, Medicare, expenditures, USA

Number of References: 37

Perspective

The article is co-authored by three health care services research professors, one health policy research professor and a palliative care research physician, all from Duke University.

Purpose of Article

The purpose of the article is to estimate lengths of hospice use associated with maximum savings in Medicare expenditures utilizing methods that reduce sample selection bias of who chooses hospice care, and account for actual length of hospice use.

Data

The study uses a random sample of Medicare beneficiaries from the 1982, 1984, 1989 and 1994 national Medicare enrollment files to identify beneficiaries age 67 and older who died between 1993 and 2003. Those with less than two years of Medicare claims, who were covered by an HMO at any time during their last year of life, or who did not incur any cost during their last year of life were excluded. Of the remaining 11,245 decedents, 1,819 died while using hospice. The final analysis sample consists of these hospice decedents and 3,638 controls (two controls for each hospice decedent case) matched via their predicted probability of dying while using a hospice using a propensity score method. For both decedent cases and matching controls, expenditures for all types of Medicare-financed care are included based on Medicare claims records.

Methods

The matching methodology used to construct the final analysis sample reduces sample selection bias. Variables used to create matches included demographic, primary health condition during last year of life, Medicare expenditures from the year prior to last year of life, Medicaid eligibility, nursing home residence during last year of life and census region. Decedent cases were matched to persons who died during the same period (1993-1996, 1997-1999, or 2000-2003), who were in the same primary health condition strata (cancer vs. others) and of the same gender. Tests of means and proportions of these variables comparing those dying in hospice to those not using hospice and to the matched controls were performed. In addition, *t*-tests of means were used to compare expenditures of hospice users and matched non-hospice users for three periods: before hospice initiation, after hospice initiation, and the entire last year of life. A particular decedent and their two controls always had similar number of days in each of these three comparison periods.

A graph of daily costs of decedent cases and controls prior to death illustrates cost differences of hospice users compared to non-users. Several graphs also illustrate cumulative cost savings of hospice users (stratified

by cancer and others) to identify the length of hospice use associated with maximum cost savings during the last year of life. A non-linear least-squares regression model with three spline segments is fit to identify the point in days when cost savings stopped increasing for each extra day of hospice use, as well as to identify the point at which savings began to decrease for each extra day of hospice use.

Results

For the full sample of 11,245 decedents, 16.1% died while receiving Medicare-financed hospice care although this percentage increased over the study period. The median length of hospice use across the entire study period from initiation until death was 15 days (mean 50 days, standard deviation 102 days), and one fourth of hospice users used such care for five days or less prior to death. Differences in some observed variables (e.g., race, age at death and some primary health conditions) between hospice users and non-users confirmed that simple comparisons of costs among the two groups are confounded by selection bias.

After accounting for selection bias and the time period hospice was actually used prior to death, hospice use reduced Medicare program expenditures by an average of \$2,309 per hospice user in 2003 dollars. Total costs for the entire last year of life did not differ between hospice users and controls. However, total costs during the last year of life prior to hospice entry were \$2,199 higher for hospice users compared to controls where this cost differential occurred primarily in the week prior to initiation of hospice. Moreover, hospice use reduced Medicare program expenditures for most days in the last three months of life; about \$10 on the 72nd day prior to death with savings increasing to \$500 four days prior to death and \$750 on the day of death.

Maximum cumulative expenditure reductions differed by one's primary health condition. For decedents whose primary condition was cancer and who used hospice for 58-103 days prior to death, the maximum cumulative reduction in Medicare expenditures per user was about \$7,000. For those with primary condition of cancer, each additional day of hospice use prior to 58 days resulted in cumulative Medicare savings increases, while for each additional day of hospice use after 103 days, cumulative Medicare savings decreased. Finally, if hospice stays in excess of 180 days were halved, a 12.5% increase in savings to the Medicare program was estimated. A similar percent increase in savings to the Medicare program would result if the length of hospice use increased by about four days for all hospice beneficiaries who used less than 180 days.

Limitations

The authors acknowledge several limitations. First, they recognize that a prospective matching approach (as opposed to their retrospective approach) is preferable as it would account more fully for the choice process that is undertaken when one contemplates hospice. Other admitted limitations include not having clinical information or cause of death data, and having to exclude persons who were enrolled in Medicare HMOs during their last year of life. Finally, the authors note their analysis does not evaluate the appropriateness of the care received by hospice users or matches, or the quality of life experienced by patients and families.

Conclusions

The savings amount to Medicare by the appropriate use of hospice is substantial. The authors argue their findings clarify conflicting conclusions of prior related studies due to this paper's accurate methodology. Given the presumptive eligibility period of the last six months of life for the Medicare hospice program, the authors suggest that more effort be placed on increasing short hospice stays as opposed to shortening longer ones. They feel the Medicare program now has a rare opportunity to reduce costs and improve quality of life.

Formal Citation

Miller, S. C., Lima, J., P. L. Gozalo and V. Mor. 2010. [The Growth of Hospice Care in U.S. Nursing Homes](#). *Journal of the American Geriatrics Society* 58(8): 1481-1488.

Subject/Category: Hospice care

Key Words: Hospice, nursing homes, end of life, Medicare, reimbursement policy

Number of References: 43

Perspective:

The article is co-authored by two health care services researchers, a research analyst and a health economist econometrician, all from the Center for Gerontology and Healthcare Research at Brown University. Three of the four authors are sponsored by the National Hospice Foundation.

Purpose of Article

The purpose of the article is to examine the relationship between the growth of hospice providers, hospice use, length of hospice stay and hospice care provided through nursing homes across U.S. states. Results are intended to educate policymakers as they consider the redesign of Medicare hospice benefits.

Data

The study combined U.S. nursing home (NH) resident assessment data (Minimum Data Set (MDS)) with Medicare enrollment and claims data from 1999 to 2006 to create comprehensive patient history files for all NH residents. NH hospice use was estimated by examining overlapping dates on hospice claims with dates on NH stays. NH decedents were defined as Medicare beneficiaries whose death occurred within one day of a NH stay or within seven days of hospice transfer from a NH. The rate of NH decedent hospice use was calculated by dividing the number of NH decedents in a calendar year receiving NH hospice care by the total number of NH decedents in that calendar year. The hospice length of stay for NH decedents receiving hospice care was determined from dates on Medicare hospice claims. The number of hospices that provided care in NHs was also determined by examining hospice claims for NH residents. The ratio of Medicare hospice care in NHs was calculated by dividing the total number of NH residents with any NH hospice (not only decedents) in a calendar year by the total number of Medicare beneficiaries in that calendar year who simply received hospice (from the Medicare and Medicaid Statistical Reports from 2001 to 2008).

Methods

Descriptive statistics on hospice provider growth, hospice decedent characteristics and the rate of NH hospice use (weighted by the number of deaths in individual states and U.S.) are presented. Statistical tests (t-test, chi-square, Breslow-Day) were used to test for observed differences and interactions. A panel data fixed-effect (within) regression analysis that controlled for differences across states was used to examine how growth in hospice providers affected NH hospice use. The regression included a year indicator variable to capture the secular time trend and number of hospices. The state-level observations in the regression were weighted by their number of confirmed NH decedents to obtain nationally representative estimates.

Results

From 1999 to 2006, Medicare-certified hospices providing care in NHs grew from 1,850 to 2,768 (50% growth), while the rate of NH decedent hospice use grew from 14% to 33% (137% growth). Regression results show that for every 10 new hospice providers within a state, there was an average state increase of 0.58% in NH hospice use. Regardless of hospice provider growth, NH hospice use increased as hospice use rates grew by 2.5% each year on average when controlling for hospice provider growth and state differences.

Demographic characteristics of NH hospice decedents changed little across study years. Most were female (67%), white (90%) and over age 85 (50% to 55%). The proportion of NH hospice decedents with non-cancer diagnoses grew from 69% in 1999 to 83% in 2006 (p -value < 0.001). The proportion of NH decedents with non-cancer (cancer) diagnoses accessing hospice increased from 12% (23%) in 1999 to 31% (51%) in 2006 (p -value < 0.001). The growth in NH hospice use was accompanied by longer mean lengths of hospice stay as the mean stay for NH decedents increased from 46 days to 93 days (p -value < 0.001) over the same time period. This result was driven by a higher proportion of long hospice stays (longer than 180 days).

There was considerable state variation in the growth of NH hospice providers, in NH hospice use and in the mean length of hospice stay from 1999 to 2006. The 10 states with the most (least) hospice provider growth incurred a 192% (101%) increase in rates of NH hospice use from 1999 to 2006. The 10 states with the most (least) hospice provider growth had a mean length of hospice stay of 131 days (95 days). At the 90th percentile, hospice stays were 173 days in 1999 and 399 days in 2006 (a 131% increase) in states with the most provider growth, whereas they were 141 and 276 days, respectively (a 96% increase) in the states with the least growth. Both groups had an increase in the proportion of NH hospice decedents with noncancer diagnoses of around 13.5%. Finally, the proportion of Medicare hospice beneficiaries in NHs to Medicare hospice beneficiaries was 22% in 1999, 24% in 2002 and remained approximately 25% through 2006.

Limitations

The authors point out several limitations. First, the match rate for residents' MDS data with their Medicare data was over 90% across study years. Second, they note that although their study shows a strong association between the growth in the number of hospices providing care in NHs and an increase in hospice use in the U.S., some states experienced greater growth rates in hospice use than others. Their study does not explore these differences across states, but they feel more research is needed on hospice provider behavior and healthcare market factors that may be influencing these differences. Lastly, they caution that the provision of NH-hospice collaborative care may appear to be the most feasible option for widespread improvements of end-of-life care among NH residents simply because of the lack of research on the effectiveness of the provision of non-hospice palliative care in U.S. NHs.

Conclusions

The recent growth in hospices providing care in NHs, in rates of NH hospice use and in the mean length of a hospice stay have important implications for the design of Medicare hospice benefits. Increased access to and utilization of hospice care in NHs has led to increased Medicare expenditures due to longer hospice stays. The authors also document several barriers to Medicare hospice benefits for those with (non-cancer) chronic terminal illnesses, despite this groups' increased NH hospice use. Hence, the authors caution that a Medicare hospice reimbursement policy that would vary beneficiary payments as a function of the length of hospice stay may seem reasonable, but it must be sensitive to the variations in hospice use in NHs, particularly the needs of dying non-cancer NH residents. Such scrutiny could result in reduced hospice enrollments and a higher prevalence of shorter hospice stays.

Formal Citation

Pyenson, B., Connor, S., K. F. Fitch and B. Kinzbrunner. 2004. [Medicare Cost in Matched Hospice and Non-Hospice Cohorts](#). *Journal of Pain and Symptom Management* 28(3): 200-210.

Subject/Category: Hospice care, Medicare

Key Words: Medicare, costs, hospice, duration until death

Number of References: 30

Perspective

The article is coauthored by a consulting healthcare actuary, a hospice and palliative care researcher, a healthcare management consultant and a research physician. The authors are from Milliman, Inc., the National Hospice and Palliative Care Organization and VITAS Healthcare Corporation.

Purpose of Article

The purpose of the article is to design a study to examine cost for subsets of patients where experts define the patient as qualifying for hospice care.

Data

The study uses the 5% Sample Beneficiary Standard Analytic Files created by the Centers for Medicare and Medicaid Services (CMS) for 1998 to 2000. This dataset contains roughly 2 million Medicare beneficiaries including about 100,000 annual deaths. For this study, patients are selected through a process (described below) that categorizes each into a diagnostic cohort based on administrative claims data information and perceived relevance to hospice. For each selected patient within each cohort, there exists a point in time (“indicative marker”) from which costs and length of life are measured. Those who incurred less than \$4,000 or more than \$115,000 in claims from the indicative marker through death are excluded, as are those who died within 15 days after the indicative marker. The sample is further restricted to patients who died within the calendar year of their indicative marker or the next calendar year. The final sample contains demographic and medical claims details (including hospice) on 8,700 patients.

Methods

A case-control process selects Medicare patients who are “deemed” candidates for electing hospice care. Patient characteristics contained in Medicare administrative data identify and sort individuals into one of 17 diagnoses according to the International Classification of Diseases, 9th Revision, clinical Modification (ICD-9-CM), the Current Procedural Terminology, Fourth Edition (CPT) and the Health Care Financing Administration Common Procedure Coding System (HCPCS). Within each diagnosis, an “indicative marker” defines a starting point in the end stage of the diagnosis from which cost and time until death are tabulated. An indicative marker consists of either an ICD-9-CM code alone or an ICD-9-CM code combined with CPT and/or HCPCS codes. All indicative markers were created and reviewed by an expert panel of oncologists, hospice medical directors, actuaries and Medicare insurance coding specialists. This sample selection methodology creates 17 diagnostic/disease cohorts where each cohort contains homogenous diagnostic patients, some of whom subsequently choose hospice care (based on one or more hospice claims).

Beginning from the date of the indicative marker, Medicare payments and time until death in days for patients electing or not electing hospice care are compared within each disease cohort. A *t*-test is used to evaluate differences in mean costs per patient. Median costs and mean and median time until death within each cohort are also reported. The significance of age, sex, Medicaid-eligibility and use or non-use of hospice care on cost and time until death is tested through a generalized linear model although no attempt is made to develop predictive parameters. SAS and Excel are used for all analyses.

Results

For the study sample of 8,700 patients, 44% chose to receive hospice care and 46% were female. Overall, a larger percent of females (48%) made up the hospice group than the non-hospice group (45%). Patients in the hospice group were slightly younger (74% less than or equal to age 79) than those in the non-hospice group (67% less than or equal to age 79). The geographic distribution by state of the hospice and non-hospice groups was similar. For the cancer diagnostic cohorts, 53% of the patients were in the hospice cohort.

The mean Medicare cost per patient was significantly ($P < 0.05$) lower for patients who chose hospice in the following three disease cohorts: congestive heart failure (\$46,793 for hospice vs. \$53,528 for non-hospice), liver cancer (\$27,364 for hospice vs. \$30,402 for non-hospice) and pancreatic cancer (\$29,621 for hospice vs. \$34,784 for non-hospice). Patients who chose hospice had a higher mean cost at this significance for stroke (\$46,910 for hospice vs. \$34,579 for non-hospice). The median Medicare costs per patient generally followed the same pattern across the cohorts. The pattern of lower costs for patients who chose hospice does not appear to be associated with shorter survival. In fact, those who chose hospice showed longer mean and median time until death than their matched non-hospice cohorts.

Limitations

The authors acknowledge several limitations of this study. First, the authors caution that since the final sample contains only those patients who died, it is of limited value for any type of survival study. Second, the study does not include race as a factor of study, although racial disparities deserve further investigation, and the study does not consider the substantial out-of-pocket costs to families for end-of-life care. Third, the administrative data used is susceptible to incomplete or inaccurate coding by healthcare providers. Finally, the authors note the study does raise temporal bias issues. Patients who choose hospice care may incur lower expenses with or without hospice care, because they simply desire to avoid aggressive treatment. This may explain some of the cost findings for various cancer diagnoses (esophagus, stomach, liver, gallbladder and pancreas) where the indicative marker was defined by the appearance of a diagnosis, rather than a more aggressive medical intervention.

Conclusions

The authors claim this study finds evidence that Medicare costs are lower for patients who choose hospice than for those who do not for specifically defined terminally ill populations. The authors further claim that among those who died in these populations, patients who chose hospice care also lived longer on average than similar patients who did not choose hospice care. The authors hope this study prompts additional research on the appropriate length of hospice enrollment needed to achieve the goals of end-of-life care and may guide physician recommendations that are both compassionate and cost effective.

Formal Citation

Campbell, D. E., Lynn, J., T. A. Louis and L. R. Shugarman. 2004. [Medicare Program Expenditures Associated with Hospice Use](#). *Annals of Internal Medicine* 140(4): 269-277.

Subject/Category: Hospice care, Medicare

Key Words: Hospice, Medicare, costs, cancer

Number of References: 62

Perspective

The article is coauthored by two health services researchers, a geriatrician and a biostatistician. Grant support was from the Agency for Healthcare Research and Quality, The National Institute on Aging, The Fan Fox-Leslie Samuels Foundation and the The Washington Home Center for Palliative Care Studies.

Purpose of Article

The purpose of the article is to estimate the effects of hospice care on Medicare program expenditures during the last year of life from 1996 to 1999 across cohorts defined by age and medical diagnosis.

Data

The study extracts data on Medicare decedents from the 1996 to 1999 Medicare claims and denominator files from the 5% Sample Beneficiary Standard Analytic Files created by the Centers for Medicare and Medicaid Services. Decedents were older than 67 years of age, had at least 36 months of continuous Part A and Part B Medicare coverage prior to death and lived in the United States. The final sample contains demographic and medical claims details (including hospice) on 245,365 deceased Medicare beneficiaries. Medicare payments (both aggregate payments and by type of service) made to providers in the last year of life are adjusted for inflation to 1999.

Methods

A stratified analysis is employed to analyze the effects of hospice enrollment on Medicare expenditures in the last year of life, overall and by service type. Cohorts are defined by age and cancer or non-cancer status, or age and principal medical condition. Within each cohort, linear regression models estimate adjusted mean Medicare expenditures in the last year of life for hospice enrollees compared to non-enrollees. A propensity score approach is used to adjust for selection bias between the hospice enrolled and non-enrolled groups including gender, race, enrollment in Medicaid, urban setting, duration of illness, comorbidity conditions, low use of Medicare, nursing home residence and year of death. To control for the disproportionate influence of very high and low Medicare use decedents, results presented are based on expenditures that were truncated at the 5th and 95th percentile of the strata-specific distributions.

Results

For the study sample of 245,365 deceased beneficiaries, 57% were female, 10% non-white, 24% Medicaid enrollees, 18% hospice enrollees, mean age at death 83, and 72%, 13% and 15% resided in a metropolitan, urban and rural areas, respectively. Characteristics varied by medical condition cohort and age where the non-

cancer cohort comprised 73% of all decedents and had an overall rate of hospice use of 10%, compared with 38% for cancer decedents. Hospice use increased slightly with age in the non-cancer cohort and decreased with age in the cancer cohort. Compared to the cancer cohort, the non-cancer cohort was older and more likely to be female, use Medicaid, have a longer duration of illness, have more coexisting conditions, live in a nursing home and have consistently low use of Medicare services in the 24 months prior to death.

Unadjusted mean Medicare program expenditures and associated expenditure ratios (hospice enrollees to non-enrollees) also varied by age and medical condition cohort. Expenditures decreased with age in all cohorts, but expenditures were greater at every age for the cancer cohort than the non-cancer cohort. The patterns of the unadjusted ratios suggest the use of hospice was associated with additional costs to the Medicare program, that these additional costs increased with age and were a function of hospice use in the non-cancer cohort. Similar patterns were observed for the ratios of adjusted mean Medicare expenditures.

Differences between estimates for adjusted mean expenditures among hospice enrollees and non-enrollees by type of expenditure were relatively precise (i.e., narrow 95% confidence intervals) and most all were statistically significant ($P < 0.05$). For those without cancer, the average hospice enrollee incurred Medicare costs of about \$2,579 more in the last year of life than those of the average non-enrollee, and their additional costs increased with age from \$1,356 at 68 to 79 years of age to \$3,725 at 85 years of age or older. For those with cancer, there appeared to be no significant difference in adjusted mean expenditures among hospice enrollees and non-enrollees across all the ages, however there were significant differences within age cohorts. Enrollees with cancer who were 68 to 79 years of age saved about \$1,703 compared to non-enrollees of the same age, while those enrollees with cancer 85 or older incurred an additional cost of \$1,193 over non-enrollees. For those with cancer who were younger than 85, the cost of hospice appeared to be offset by savings in all other types of service expenditures except outpatient facility use. In contrast, estimated savings among the non-cancer cohort for hospital inpatient, skilled-nursing facility, outpatient facility and physician or supplier services did not offset the costs of hospice and increased spending for home health care among hospice enrollees. The authors note that results were robust to utilizing untransformed or log-transformed expenditures or limiting the continuous enrollment requirement to 12 rather than 36 months.

Limitations

The authors note three limitations of this study. First, they acknowledge that while their methods attempt to control for selection bias and other confounders, some selection bias and confounding inevitably remains. Second, their results are limited to Medicare expenditures exclusively and do not pertain to the effect of Medicare's hospice benefit on expenditures in the last year of life by other parties (family, Medicaid, out-of-pocket). Finally, the authors infer that an appropriate evaluation of the merits of the hospice benefit involves more than simply examining its effects on Medicare program expenditures. One must consider the effect of hospice on quality of life, the impact on expenditures from all sources and alternatives for end-of-life care.

Conclusions

This study finds evidence that hospice use reduces Medicare expenditures for patients with cancer who are younger than 85, but increases Medicare costs for patients without cancer as well as all patients older than 85 years of age. The authors suggest the variation in the effects of use of hospice on costs arises from different trajectories of service needs and prognostic certainty that are associated with patients' diagnoses and ages. The overall merit of hospice use requires a comprehensive understanding of the benefits, as well as the costs of hospice care.

Formal Citation

H. Groninger. 2012. [A Gravely Ill Patient Faces the Grim Results of Outliving Her Eligibility for Hospice Benefits](#). *Health Affairs* 31(2): 452-455.

Subject/Category: Hospice care, Medicare

Key Words: Hospice care, Medicare, cost

Number of References: 0

Perspective

The author is a staff clinician with the Pain and Palliative Care Service at the National Institutes of Health Clinical Center and was previously a home hospice medical director.

Purpose of Article

The purpose of the article is to use a professional case experience to highlight the limitations of the current Medicare hospice benefit and offer suggestions on how it could be improved.

Data

The narrative nature of the article does not directly utilize any data.

Methods

The article discusses the case of an elderly ill woman, dubbed “Mrs. R.,” who is discharged from home hospice care supported by Medicare and eventually dies in a hospital’s intensive care unit (ICU).

Results

Mrs. R., a lifetime smoker, developed chronic obstructive pulmonary disease (COPD). After an episode that caused her to spend two weeks on a ventilator, she was placed in Medicare funded home hospice care with a short-run survival prognosis of less than six months. At home, her condition stabilized with no hospital visits for ten months. At this point, her pulmonologist determined that he was not certain she had less than six months to live, so he did not sign the certification that would allow her to remain eligible for the Medicare hospice benefit. Six weeks later, Mrs. R. awoke with acute shortness of breath. Without a hospice nurse on call, she was taken by ambulance to a nearby hospital. She was placed on a ventilator for a week. Once it became clear that she would not recover, life support was withdrawn and Mrs. R. passed away in the ICU rather than in her preferred home location.

Based on his experience as the hospice medical director for this particular case, the author highlights a number of flaws in the design of the Medicare hospice benefit that contributed to Mrs. R.’s undesired outcome. First, the hospice benefit is intended to be provided for no more than six months in that if a patient is not expected to die within six months “if the disease runs its usual course,” the hospice benefit should not be offered. Such a prognostication can be extremely difficult for clinicians, especially when a patient has an unpredictable disease such as COPD. The author notes that the hospice benefit is the only Medicare benefit that is based on prognostication rather than actual service needs. Consequently, one finds cases like Mrs. R., who outlived her Medicare hospice benefit and spent her final days in the ICU rather than her desired home

location. More commonly, one also finds cases where a patient dies very quickly after one acute episode, so there is no time for the hospice benefit to create a stable, comfortable transition, suggesting that some patients should receive a form of home-based palliative care before any episode occurs. Another issue discussed is the hospice benefit's reimbursement policy, which pays \$150 per patient, per day, regardless of services provided. The author argues this policy incentivizes hospice agencies to admit and recertify patients who do not require expensive treatments. The author also believes recent legislation in the Affordable Care Act of 2010 intended to address this issue is merely a myopic attempt to cut costs and reduce inappropriate use of services that may actually adversely affect current hospice patients.

The author offers several suggestions to rectify these flaws. One suggestion is to base hospice benefit eligibility on the need for the types of services hospice care provides as opposed to prognostication. He suggests paying hospice agencies on a graduated per diem, reflecting the intensity of patient care, or on a modified fee-for-service basis where payment is based on diagnosis. Finally, the author offers another alternative altogether: replace the Medicare hospice benefit with a home-based palliative care benefit such as the one studied by Brumley et al. in their July 2007 article in the *Journal of the American Geriatrics Society*. This alternative benefit has the potential to reduce costs, prevent patient hospitalizations and improve patient satisfaction.

Limitations

None

Conclusion

The article examines the current limitations of the Medicare hospice benefit through the real case of an elderly lady in the final stages of life. The author demonstrates how the Medicare hospice benefit is not allocated to the correct patients for the correct amount of time. By changing the design of this benefit to better reflect the needs of the patient, the author feels end-of-life costs could be reduced and end-of-life care could be improved.

Formal Citation

Rhee, Y., Degenholtz, H. B., A. T. Lo Sasso and L. L. Emanuel. 2009. [Estimating the Quantity and Economic Value of Family Caregiving for Community-Dwelling Older Persons in the Last Year of Life](#). *Journal of the American Geriatrics Society* 57(9): 1654-1659.

Subject/Category: Informal family caregiving

Key Words: Informal care use, economic value of caregiving, Health and Retirement Study (HRS), end of life

Number of References: 28

Perspective:

The article is coauthored by an academic psychiatrist, two health policy academics and a research physician.

Purpose of Article

The purpose of the article is to provide national estimates of the quantity and economic value of informal family caregiving provided to older persons during their final year of life. Results are intended to help policymakers understand the role of unpaid assistance provided to people at the end-of-life.

Data

The study uses a sample of 990 individuals from the biennial Health and Retirement Study (HRS) who were alive in 2000, died by 2002 and did not move to a nursing home (or hospice) during this 2-year period. Data on decedents are extracted from the 2000 survey. These variables include demographic characteristics, chronic health problems, health behaviors, healthcare services used, net worth, physical and cognitive functions, family networks, living arrangement, caregivers' relationship and insurance. Data on decedents' caregivers are abstracted from a set of ancillary files from the 2002 HRS survey that are uniquely linked with the decedents in the main survey. Information from these ancillary files on the quantity of informal caregiving (i.e., unpaid assistance with activity of daily living (ADL) and instrumental activity of daily living (IADL) tasks) is used to estimate the dependent variable, the total hours (or logarithm) of informal caregiving per week for each decedent.

Methods

Univariate descriptive statistics related to decedents and family caregivers are presented. Ordinary least squares (OLS) regression is used to estimate the total average weekly informal caregiving hours per decedent, the effect of the independent variables on the amount of informal care and the total hours of informal care over the full sample. To estimate the replacement cost for the predicted informal care hours, Duan's smearing retransformation is applied. These adjusted, informal care hours are then multiplied by the 2002 national average home aide wage and 52 weeks to derive annual cost estimates.

Results

For the sample of community-dwelling older people, weighted to be representative of the U.S., the average age of death is 76.6, just over half are male, just under half are married and over two-thirds are white. Average net worth is about \$239,000 while the median is just over \$99,000. Slightly less than half the sample received

caregiver care where the unadjusted, average informal number of care hours was 53.2 hours per week per care recipient. For these recipients, each had an average of 1.8 informal caregivers where spouses and daughters were the most common types of caregivers.

The OLS regression indicates that older persons who lived with their children received more informal care as did those with greater physical difficulties. Married, older persons were significantly less likely to receive informal care relative to those widowed, divorced or separated, or never married. The predicted average weekly adjusted number of informal care hours is 65.8 per recipient and the predicted average weekly adjusted number of informal hours provided is 36.6 per individual caregiver. This translates to estimated midrange annual replacement costs of \$31,342 for informal care provided to a recipient, and \$17,412 for informal care provided per individual caregiver in 2002 dollars. The total midrange estimated economic value of informal caregiving in communities during the final year of life is \$1.46 billion for the weighted population in the U.S. Family caregivers provide a significant amount of informal end-of-life care that comes at a real economic cost to society based on lost productivity and, according to other cited studies, increased morbidity and mortality of caregivers.

Limitations

The authors acknowledge several limitations. First, the authors eliminate 511 subjects from the sample who moved to a nursing home prior to death as it was not possible to accurately attribute hours of informal care to this group. Second, they discuss the potential endogenous relationship between the amount of informal care provided to older people and the availability of formal care as one may act as a substitute or complement of the other. Third, they voice concern about the accuracy of caregiving estimates by family members as it may be difficult to distinguish between household duties and caregiving assistance. Fourth, the authors recognize their replacement costs are based on several simplifying assumptions about the potential for home health aides to truly substitute for family caregiving. Finally, the authors note their estimates of the value of informal caregiving are most likely underestimates as they do not take into account other indirect costs of caregivers such as lost time from work or psychological burdens.

Conclusions

The amount and economic value of informal care provided to individuals in their last year of life by family members is substantial. The authors estimate 65.8 hours per week of informal care are provided. This same amount of weekly care provided by a home health aide would annually cost between \$22,514 and \$42,351 (in 2002). The total economic value for the U.S. would be \$1.4 billion based on a weighted population. The authors suggest that long-term care and hospice care programs should expand to reduce the negative effect of caregiving on family caregivers but not in such a way that discourages people from providing such assistance.

Formal Citation

Donley, G., and M. Danis. 2011. [Making the Case for Talking to Patients about the Costs of End-of-Life Care](#). *Journal of Law, Medicine & Ethics* 39(2): 183-193.

Subject/Category: Patient communication, cost, ethics

Key Words: Treatment planning, patient communication, cost, health care decision making

Number of References: 43

Perspective

The article is co-authored by a researcher and a physician who are both in the Department of Bioethics at the Clinical Center of the National Institutes of Health.

Purpose of Article

The purpose of the article is to articulate the challenges and benefits of having end-of-life costs become part of the initial and ongoing dialogue between physicians and patients. The article also suggests how and when such an introduction in the dialogue should occur with the objective of more cost-conscious and informed joint decision making by both parties on possible treatments.

Data

The opinion-oriented nature of the article does not directly utilize any data. The article references related research based on empirical data as well as survey data on health care recipients and providers.

Methods

The article presents arguments that encourage the need for increased and early discussions of end-of-life costs by physicians treating terminally ill patients.

Results

In the U.S. there is concern over recent and projected increases in health care expenditures as health care spending approaches 25 percent of gross domestic product. A significant portion of these expenditures funds end-of-life care as evidenced by the relatively stable 25 percent of annual Medicare payments attributable to patients in their last year of life. These aspects of health care spending help motivate the authors' arguments regarding increased and transparent discussions of end-of-life costs between physicians and patients that may lead to an aggregate reduction in health care expenditures as well as more optimal decision making.

The authors first distinguish between two types of health care costs at the end of life. Societal costs are shared costs of health care incurred through mechanisms such as insurance premiums or taxes. Personal costs are individual costs incurred at the time of the patient's illness and even after the end of life. The authors reason that patients respond more to personal costs coming from their own pockets rather than considering costs when others contribute (like insurance or trade-offs of other goods and services). In addition, terminally ill patients are aware of the financial burden their illness can place on themselves and significant others during both the time of their illness and after their lives have ended. These patients may also experience additional anxiety and helplessness due to the costs that their caregivers outside of the medical arena incur.

In providing ethical justification for physicians discussing end-of-life costs with patients, the authors assume that physicians greatly influence the type of care patients receive and are thus in a position to determine how health care resources are allocated. They propose that physicians make decisions about health care resources via three approaches: 1) resource constraints placed on them by institutions, 2) rules of medical practice (e.g. triage policies), and 3) clinical judgment when the first two approaches do not apply. The authors believe it is appropriate for physicians to initiate the conversation of cost of various treatment plans as it will enable more informed decision making by both patients and physicians. Furthermore, the authors feel this discussion of costs is optimal to the alternatives of bedside rationing by physicians (without informing patients of costs) or simply opting for the most effective treatment regardless of costs. The former alternative can lead to an inequitable distribution of resources while the latter contributes to increasing health care costs.

The authors describe both the nature and timing of the end-of-life costs discussion between physicians and patients. They cite research that shows patients are receptive to discussions of personal costs during clinical encounters; especially when physicians are empathetic to cost concerns. A narrative example is provided of how a doctor can introduce the concept of personal costs to a patient in a way that allows the patient to control how they want costs to factor into subsequent treatment discussions. The authors encourage discussion of health care costs from onset of the chronic or terminal condition throughout the illness trajectory so that attention to financial consequences becomes routine. They also encourage “effectively and sensitively” incorporating financial considerations in advanced care planning so patients have sufficient time to evaluate their own objectives while they have the capacity to do so. This also relieves patients’ next of kin from making difficult treatment decisions for the terminally ill relative.

Throughout the article the authors highlight the varying and unpredictable individual preferences that end-of-life patients may have on issues such as quality of life versus length of life, religious beliefs, what a “good” dying experience entails, and even personal family pressures. The authors feel these variations in addition to the varied end-of-life experiences and varied financial resources of end-of-life patients reinforce the importance of transparent discussions about the costs of possible treatment plans.

Limitations

The authors provide three caveats. First, they caution that lower-income and less educated patients may bear a greater burden in reducing overall health care costs as they are more likely to forego more expensive end-of-life treatments or be unaware of care they are actually entitled to receive. Second, the authors acknowledge that in order for physicians to have discussions with patients about the financial aspects of treatment plans, they need significant time, resources and information. These requirements may not always be available. Finally, they warn against physicians conducting these conversations in ways that are confusing or overwhelming to patients, which may itself be difficult for physicians to judge.

Conclusions

The authors suggest that it is optimal for clinicians to explicitly cover the topic of end-of-life health care costs with their patients early and often in their treatment discussions. It increases patients’ engagement in the treatment decision making process where trade-offs between costs and expected benefits of different strategies must often be considered. It also allows patients and families sufficient time to make the right decisions for themselves rather than making potentially hasty decisions at the end of the illness trajectory.

Formal Citation

E. J. Emanuel. 1996. [Cost Savings at the End of Life: What Do the Data Show?](#) *Journal of the American Medical Association* 275(24): 1907-1914.

Subject/Category: Research design

Key Words: Research methodology, hospice, advanced directives, end-of-life cost, selection bias

Number of References: 42

Perspective

The article is authored by a research physician from the Center for Outcomes and Policy Research at Harvard Medical School.

Purpose of Article

The purpose of the article is to review the literature from the 1980s to the mid-1990s when the article was published to determine pertinent factors regarding whether there are cost savings from using hospice or advance directives.

Data

The article utilizes no primary data but summarizes results from and provides a conceptual critique of the published literature.

Methods

The articles considered the “major studies,” both randomized trials and observational studies, were summarized and critiqued to determine whether any end of life savings resulted from comparing alternative paths. In assessing the studies five key factors were addressed and summarized: (a) selection bias; (b) time frame of assessment; (c) types of medical costs evaluated; (d) data reporting; and (e) generalizability.

Results

- (a) Selection Bias: The concern for observational studies is that there is a fundamental difference in personal behavior for those who chose to enter a hospice or create an advance directive. These differences in people are difficult to assess and control in an observational study. Preferences by people for less aggressive care or whether they would act on their preferences are not available in administrative or claims data. Randomized studies do not show any cost savings between interventions.
- (b) Time Frame of Assessment: There are two natural ways of measuring cost data. One is retrospectively, such as last six or 12 months before death, while the second is prospectively, such as time since enrolling in hospice. For the first approach, critics suggest that when the choice of hospice or advanced directive is chosen within that time frame, then the costs are mixed and conclusions are hard to draw. For the second approach, the difficulty is choosing an appropriate time frame for the control group as they do not have an intervention time point as for the hospice intervention. Advanced directives are hard to assess as they can be completed well in advance of any end of life process starting. Studies have found

that the longer the time period to assess leads to more costs and the intervention does not look as favorable.

- (c) Types of Medical Costs Assessed: Most studies on advanced directives and some involving hospice have focused on hospital expenditures or Medicare Part A expenditures. Hospital expenditures are easily obtained and missing data is minimized. However, outpatient expenditures may be a substantial amount and excluding these could lead to unwarranted conclusions. Expanding to Medicare Part B expenditures only is not complete, as many older adults have medical expenditures outside of the Medicare Program. (As an aside, this article was published prior to introduction of Medicare Parts C and D.) Finally, most studies include direct medical costs and omit costs for caretakers' burdens, financially, physically and psychologically.
- (d) Reporting of Savings: Some studies report savings in terms of dollars saved, others report a percentage saved. The results of studies may be similar, but presented differently, such as savings of \$0.50 for every dollar spent versus a 33% savings.
- (e) Generalizability: Cancer patients are very different from other terminal patients. They receive somewhat accurate predictions about time until death and have time to complete an advanced directive if desired. Thus reporting of savings may differ between groups of people with different conditions.

The paper concludes with a case study to illustrate these concepts.

Limitations

There are no limitations in this article, per se, but issues are raised that are suggested to be considered in future studies.

Conclusions

The author has raised issues that need to be addressed in studies concerning costs of the end of life process. He notes that better data is needed through perhaps a large randomized study or a prospective study that allows patient preferences and socio-demographic factors to be collected. In addition, indirect costs need to be assessed and included in the results.

Formal Citation

Bach, P. B., D. Schrag, and C. B. Begg. 2004. [Resurrecting Treatment Histories of Dead Patients: A Study Design That Should Be Laid to Rest](#). *Journal of the American Medical Association* 292(22): 2765-2770.

Subject/Category: Research design

Key Words: Research, selection bias, medical records, terminal care, quality of health care

Number of References: 35

Perspective

The article is co-authored by two research physicians and a biostatistician who were all in the Health Outcomes Research Group in the Department of Epidemiology and Biostatistics at Memorial Sloan-Kettering Cancer Center.

Purpose of Article

The purpose of the article is to assess the underlying assumption that studying treatment histories of patients prior to their death is equivalent to studying treatment histories of patients who are dying. If this assumption is not valid, then conclusions of many studies about the quality or type of care provided to dying patients may be invalid and related recommendations may be misguided.

Data

The article utilizes data from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Tumor Registry, which is available for patients of all ages diagnosed through 2000 with survival data through 2002. The article also uses information on Medicare claims for patients diagnosed through 1999.

Methods

Population-based groups of individuals with different types of cancer are used to construct examples that demonstrate how cohort studies differ from case studies as applied to examining terminally ill patients. (In a cohort study, the subject's eligibility requirement, such as diagnosis of a terminal disease, precedes events of interest, such as medical care received by the subject. In a case study, events of interest, such as medical care received for some defined time interval prior to the death of the subject precede the eligibility requirement, such as the death of the subject.) The authors use the number of deaths and mortality rates of women diagnosed with invasive breast cancer in 2000 to show how differently subjects can be identified in a cohort study of the dying versus a case study of decedents. They use survival times for subjects aged 65 years or older diagnosed between 1992 and 1999 with stage IIIB non-small-cell lung cancer to show how the time periods of observation of subjects in a cohort study can dramatically differ from those of a case study. Analysis of the average percentage of subjects receiving chemotherapy each month during the months prior to death is used to show the magnitude of the bias that can result from the mismatch in time periods of observation. Finally, the authors use the average expenditures for "typical" patients in different age categories who are diagnosed with stage IV colorectal cancer to demonstrate the systematic bias that results when the mismatches between case studies of decedents and cohort studies of the dying are systematically associated with subject characteristics, in this case age.

Results

Although cohort studies of the dying and case studies of decedents may appear conceptually similar, the underlying differences in their design yield different results. Cohort studies differ from case studies in two substantial ways. The first is in how subjects are identified which can result in a different set of subjects than in a case study approach. As the authors demonstrate in their examination of women diagnosed with breast cancer, the subjects in the two types of studies differ because subjects who are expected to die in the near future do not always do so, while subjects who do die are not always terminally ill. Such a mismatch of subjects can occur in other settings, such as hospice or ICU studies, where terminally ill patients are investigated.

The second way cohort studies of the dying differ from case studies of decedents is the time periods of observation of the care rendered to subjects relative to when they become eligible for the study. The authors use the distribution of survival times of elderly individuals diagnosed with lung cancer to show how a case study of decedents anchored from the date of subjects' death to one year prior to death can result in a mixture of time periods extending past individual subjects' date of terminal diagnosis. The authors further show how this mismatch can lead to biases of large magnitude by examining the average percentage of subjects who received chemotherapy each month during the months prior to their death. These biases result because treatment rates determined in case studies of decedents are extremely sensitive to the selection of the look-back duration (in this example one year), and ultimately do not reflect the true treatment rates.

The mismatches in the subjects and the time period of observation between cohort studies of the dying and case studies of decedents may be systematically associated with subject characteristics related to mortality, such as age or gender. The authors illustrate how such a scenario can result in systematic bias and inaccurate conclusions regarding Medicare expenditures on colorectal cancer patients in different age groups. Because of the systematic bias present, care received prior to death will vary by age, even if care provided to dying individuals does not. Further, the systematic bias leads to gross overstatement of treatment expenditures for younger groups versus older groups.

Limitations

The authors comment that their aim is not to diminish the importance of the questions on end-of-life care that are pursued by studies designed as case series of decedents. Rather, their objective is to focus on the problematic design of sampling decedents which can lead to large biases in results. Limiting the population of decedents who are studied or shortening the duration of time prior to death that is examined may reduce these biases, but will not eliminate them.

Conclusions

The article shows that the way subjects are identified and the time periods that are examined in studies of care rendered to patients prior to their death (case study of decedents) can result in a biased depiction of terminal care when compared to studies of dying patients (cohort studies of the dying). The mismatches in subjects and time period of observations will be present in all comparisons between cohort studies and case studies of decedents because they are due to stochastic variation in survival probability and survival time.

Formal Citation

J. L. Palmer. 2004. [Analysis of Missing Data in Palliative Care Studies](#). *Journal of Pain and Symptom Management* 28(6): 612-618.

Subject/Category: Research design

Key Words: Missing data, palliative care, sensitivity analysis

Number of References: 10

Perspective

The article is authored by a biostatistician at the University of Texas M. D. Anderson Cancer Center.

Purpose of Article

The purpose of the article is to show through an example, using data from a palliative care study, the impact of missing data on the results using commonly used approaches for missing data.

Data

The author of this paper is also one of the authors of Bruera et al. (2004), a double-blind randomized trial, examining the differences of the use of methadone versus morphine as a pain medication for cancer over a 4-week span. This paper considers the issues of missing data and uses the data from the randomized trial to illustrate the impact of missing data that is related to the outcome of the study and cannot be considered missing at random.

Methods

The randomized study included 103 cancer patients who required pain control and were randomized to a methadone group or a morphine group. The methadone group had a significantly greater drop-off rate (22%) versus 6% in the morphine group ($p = 0.019$). The authors acknowledged that data were not missing at random and classified the drop-outs as “non-responders.” The data were compared between responders and non-responders. The overall conclusion was that methadone did not produce better results than morphine as a first-line option for the treatment of cancer pain, but that a future study to analyze the impact of missing data would be beneficial.

Methods tested in this article compared three methods: (a) include only complete records; (b) imputation by substituting the baseline measure for the missing data; or (c) imputation by substituting the last known measure for the missing data. Missing data occurred if patients were removed from the study due to intractable pain, if no pain relief, developed new pain or nausea prevented them from receiving two consecutive doses. In addition, patients withdrew voluntarily or by death. More patients withdrew from the methadone group than the morphine group.

Results

The data showed that those in the methadone group showed rising sedation scores (i.e., better outcomes) and greater patient drop-out. Also in this group, some patients dropped out early as their initial sedation score was zero (i.e., no benefit) at baseline. The morphine group also had some drop-out when sedation scores were

high. The author examined the three methods of analyzing missing data for the impact of pain, sedation, and nausea to see if there were group effects, time effects or interaction effects. Different conclusions would be reached depending on the method used to handle missing data. As an example, for the group effects, the results for sedation are different when the patients are excluded if missing data present (p-value = 0.23) versus baseline imputation (p-value = 0.09) or last value imputation (p-value = 0.06). Similar observations are found for the significance of time effects of pain and interaction effects of time with sedation.

Limitations

No limitations, as the purpose was to introduce a level of caution when analyzing the method for missing data.

Conclusions

Studies regarding end of life care will necessitate decisions on how to handle missing data. The decision on the method will influence the results. The author states that the approach of only including complete cases is the most subject to bias when the outcome is related to the reason for missingness. The approach of substituting the baseline value is also subject to difficulties when there are vast changes in the value from baseline for others in the study. The last method of substituting the last known value is the least subject to bias when scores are steady over time. In the end, the approach does depend on the data and the study and there is no one fix that can be used across all studies. To be transparent, the author suggests reporting different methods of dealing with missing data to show the range of potential conclusions.

Citations

35 Summarized Articles						
Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/Category: Cost</i>						
Medical Expenditures during the Last Year of Life: Findings from the 1992-1996 Medicare Current Beneficiary Survey	2002	Hoover, D. R., Crystal, S., Kumar, R., U. Sambamoorthi and J. C. Cantor	Health Services Research	37	6	1625-1642
Long-Term Trends in Medicare Payments in the Last Year of Life	2010	Riley, G. F., and J. D. Lubitz	Health Services Research	45	2	565-576
<i>Subject/Category: Cost, Canadian experience</i>						
Cost Trajectories at the End of Life: The Canadian Experience	2009	Fassbender, K., Fainsinger, R. L., M. Carson and B. A. Finegan	Journal of Pain and Symptom Management	38	1	75-80
<i>Subject/Category: Cost, demographics</i>						
Influence of Age on Medicare Expenditures and Medical Care in the Last Year of Life	2001	Levinsky, N. G., Yu, W., Ash, A., Moskowitz, M., Gazelle, G., O. Saynina and E. J. Emanuel	Journal of the American Medical Association	286	11	1349-1355
Demographic and Social Characteristics and Spending at the End of Life	2009	Shugarman, L. R., S. L. Decker and A. Bercovitz	Journal of Pain and Symptom Management	38	1	15-26
<i>Subject/Category: Cost, end-of-life preferences</i>						
Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care	2007	Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., McIlwane, J., K. Hillary and J. Gonzalez	Journal of the American Geriatrics Society	55	7	993-1000
Cost and Non-Clinical Outcomes of Palliative Care	2009	Smith, T. J. and J. B. Cassel	Journal of Pain and Symptom Management	38	1	32-44
<i>Subject/Category: Cost, ethics</i>						
Costs and End-of-Life Care in the NICU: Lessons from the MICU?	2011	Lantos, J. D., and W. L. Meadow	Journal of Law, Medicine & Ethics	39	2	194-200
<i>Subject/Category: Cost, international</i>						
The Costs of Treating Terminal Patients	2010	Simoens, S., Kuttan, B., Keirse, E., Berghe, P. V., Beguin, C., Desmedt, M., Deveugele, M., Leonard, C., D. Paulus and J. Menten	Journal of Pain and Symptom Management	40	3	436-448
<i>Subject/Category: Cost, treatment trends</i>						
Trends in Inpatient Treatment Intensity among Medicare Beneficiaries at the End of Life	2004	Barnato, A. E., McClellan, M., B., C. R. Kagay and A. M. Garber	Health Services Research	39	2	363-375

Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/ Category: End-of-life care quality</i>						
Bereaved Family Member Perceptions of Quality of End-of-Life Care in U.S. Regions with High and Low Usage of Intensive Care Unit Care	2005	Teno, J. M., Mor, V., Ward, N., Roy, J., Clarridge, B., J. E. Wennberg and E. S. Fisher	Journal of the American Geriatrics Society	53	11	1905-1911
<i>Subject/ Category: End-of-life care resource utilization</i>						
Use of Hospitals, Physician Visits, and Hospice Care During Last Six Months of Life Among Cohorts Loyal to Highly Respected Hospitals in the United States	2004	Wennberg, J. E., Fisher, E. S., Stukel, T. A., Skinner, J. S., S. M. Sharp and K. K. Bronner	British Medical Journal	328	7440	607-611
<i>Subject/ Category: End-of-life definition</i>						
A Demographic and Prognostic Approach to Defining the End of Life	2005	E. B. Lamont	Journal of Palliative Medicine	8	Supp. 1	S12-S21
<i>Subject/ Category: End-of-life patient assessment</i>						
Evaluation of Patients with Advanced Cancer Using the Karnofsky Performance Status	1980	Yates, J.W., B. Chalmer and F.P. McKegney	Cancer	45	8	2220-2224
The Karnofsky Performance Status Scale: An Examination of its Reliability and Validity in a Research Setting	1984	Mor., V., Laliberte, L., J.N. Morris and M. Wiemann	Cancer	53	9	2002-2007
Prediction of Life-Expectancy in Hospice Patients: Identification of Novel Prognostic Factors	1993	Rosenthal, M. A., GebSKI, V. J., R. F. Kefford and R. C. Stuart-Harris	Palliative Medicine	7	3	199-204
Palliative Performance Scale (PPS): A New Tool	1996	Anderson, F., Downing, G. M., Hill, J., L. Casorso and N. Lerch	Journal of Palliative Care	12	1	5-11
<i>Subject/ Category: End-of-life preferences</i>						
Racial and Ethnic Differences in Preferences for End-of-Life Treatment	2009	Barnato, A. E., Anthony, D. L., Skinner, J., P. M. Gallagher and E. S. Fisher	Journal of General Internal Medicine	24	6	695-701
Good End-of-Life Care: Perspectives of Middle-Aged and Older Singaporeans	2012	Malhotra, C., Chan, A., Do, Y. K., R. Malhotra and C. Goh	Journal of Pain and Symptom Management	4	2	252-263
<i>Subject/ Category: Ethics and legal aspects of patient care</i>						
The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives	2005	Perry, J. E., L. R. Churchill and H. S. Kirshner	Annals of Internal Medicine	143	10	744-748
<i>Subject/ Category: Financing</i>						
Financing End-of-Life Care in the USA	2001	Raphael, C., J. Ahrens, and N. Fowler	Journal of the Royal Society of Medicine	94	9	458-461

Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/Category: Financing (con't)</i>						
Does Major Illness Cause Financial Catastrophe?	2010	Cook, K., D. Dranove and A. Sfekas	Health Services Research	45	2	418-436
The Ethical Implications of Health Spending: Death and Other Expensive Conditions	2011	Crippen, D., and A. E. Barnato	Journal of Law, Medicine & Ethics	39	2	121-129
<i>Subject/Category: Health care access</i>						
Health Care Accessibility for Chronic Illness Management and End-of-Life Care: A View from Rural America	2011	Artnak, K. E., R. M. McGraw and V. F. Stanley	Journal of Law, Medicine & Ethics	39	2	140-155
<i>Subject/Category: Healthcare spending, ethics</i>						
When Care Is Worth It, Even if End Is Death	2011	P. B. Bach	New York Times	12/12/2011		
<i>Subject/Category: Hospice care</i>						
What Length of Hospice Use Maximizes Reduction in Medical Expenditures Near Death in the US Medicare Program?	2007	Taylor Jr., D. H., Ostermann, J., Van Houtven, C. H., J. A. Tulsky and K. Steinhauser	Social Science & Medicine	65	7	1466-1478
The Growth of Hospice Care in U.S. Nursing Homes	2010	Miller, S. C., Lima, J., P. L. Gozalo and V. Mor. 2010	Journal of the American Geriatrics Society	58	8	1481-1488
<i>Subject/Category: Hospice care, Medicare</i>						
Medicare Cost in Matched Hospice and Non-Hospice Cohorts	2004	Pyenson, B., Connor, S., K. F. Fitch and B. Kinzbrunner	Journal of Pain and Symptom Management	28	3	200-210
Medicare Program Expenditures Associated with Hospice Use	2004	Campbell, D. E., Lynn, J., T. A. Louis and L. R. Shugarman	Annals of Internal Medicine	140	4	269-277
A Gravely Ill Patient Faces The Grim Results Of Outliving Her Eligibility For Hospice Benefits	2012	H. Groninger	Health Affairs	31	2	452-455
<i>Subject/Category: Informal family caregiving</i>						
Estimating the Quantity and Economic Value of Family Caregiving for Community-Dwelling Older Persons in the Last Year of Life	2009	Rhee, Y., Degenholtz, H. B., A. T. Lo Sasso and L. L. Emanuel	Journal of the American Geriatrics Society	57	9	1654-1659
<i>Subject/Category: Patient communication</i>						
Making the Case for Talking to Patients about the Costs of End-of-Life Care	2011	Donley, G., and M. Danis	Journal of Law, Medicine & Ethics	39	2	183-193
<i>Subject/Category: Research design</i>						
Cost Savings at the End of Life: What Do the Data Show?	1996	E. J. Emanuel	Journal of the American Medical Association	275	24	1907-1914
Resurrecting Treatment Histories of Dead Patients: A Study Design That Should Be Laid to Rest	2004	Bach, P. B., D. Schrag, and C. B. Begg	Journal of the American Medical Association	292	22	2765-2770

Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/Category: Research design (con't)</i>						
Analysis of Missing Data in Palliative Care Studies	2004	J. L. Palmer	Journal of Pain and Symptom Management	28	6	612-618
65 Additional Articles						
<i>Subject/Category: Cost</i>						
A Longitudinal Study of the Effects of Age and Time to Death on Hospital Costs	2003	Seshamani, M. and A. M. Gray	Journal of Health Economics	23	2	217-235
Accounting for the Costs of Caring Through the End of Life	2004	Seninger, S., I. Brock, A. E. Cuellar, C. D'Onofrio, J. E. Lafata, J. Englehardt, J. Gao, T. Hu, C. A. Lockhart, S. H. Miles, G. Miller, H. A. Rosefield, D. G. Smith, B. Volk-Craft, and A. Wilkinson	Promoting Excellence in End-of-Life Care			1-36
Differences in Medicare Expenditures During the Last 3 Years of Life	2004	Shugarman, L. R., D. E. Campbell, C. E. Bird, J. Gabel, T. A. Louis, J. Lynn	Journal of General Internal Medicine	19	2	127-135
Economic Evaluation in Critical Care Medicine	2006	Cox, H. L., K. B. Laupland, and B. J. Manns	Journal of Critical Care	21	2	117-124
Prescription Drug Spending for Medicare+Choice Beneficiaries in the Last Year of Life	2006	Fahlman, C., J. Lynn, D. Doberman, J. Gabel, and M. Finch.	Journal of Palliative Medicine	9	4	884-893
Nonclinical Outcomes of Hospital-Based Palliative Care	2006	White, K. R., K. G. Stover, J. B. Cassel, and T. J. Smith	Journal of Healthcare Management	51	4	260-273
Age and Gender Differences in Medicare Expenditures and Service Utilization at the End of Life for Lung Cancer Decedents	2008	Shugarman, L. R., C. E. Bird, C. R. Schuster, and J. Lynn	Women's Health Issues	18	3	199-209
Does Age or Life Expectancy Better Predict Health Care Expenditures?	2008	Shang, B. and D. Goldman	Health Economics	17	4	487-501
Hospice Effect on Government Expenditures among Nursing Home Residents	2008	Gozalo, P. L., S. C. Miller, O. Intrator, J. P. Barber, and V. Mor	Health Services Research	43	1	134-153
Aging Diseases - Do They Prevent Preventive Health Care from Saving Costs?	2009	Gandjour, A.	Health Economics	18	3	355-362
The Cost of End-of-Life Care : A New Efficiency Measure Falls Short of AHA/ACC Standards	2009	Neuberg, G. W.	Circulation: Cardiovascular Quality and Outcomes	2009	2	127-133
Costs of End-of-Life Care: Findings from the Province of Saskatchewan	2009	Hollander, M. J.	Healthcare Quarterly	12	3	50-58
Improving Efficiency and Value in Palliative Care with Net Benefit Regression: An Introduction to a Simple Method for Cost-Effectiveness Analysis with Person-Level Data	2009	Hoch, J. S.	Journal of Pain and Symptom Management	38	1	54-61

Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/Category: Cost (con't)</i>						
Optimizing Decision Making and Resource Allocation in Palliative Care	2009	Haycox, A.	Journal of Pain and Symptom Management	38	1	45-53
Impact of Predictive Model-Directed End-of-Life Counseling for Medicare Beneficiaries	2010	Hamlet, K. S., A. Hobgood, G. B. Hamar, A. C. Dobbs, E. Y. Rula, and J. E. Pope	American Journal of Managed Care	16	5	379-384
Micro Data Analysis of Medical and Long-Term Care Utilization Among the Elderly in Japan	2010	Hashimoto, H., H. Horiguchi, and S. Matsuda	International Journal of Environmental Research and Public Health	7	8	3022-3037
Need to Cut \$1.3 Million from Budget? It Can Be Done	2011	Borginis III, W., M. Haynor, and M. Horsley	Hospice Management Advisor	16	9	97-108
Bending the Cost Curve in Cancer Care	2011	Smith, T. J. and B. E. Hillner	New England Journal of Medicine	364	21	2060-2065
Medical Spending and the Health of the Elderly	2011	Hadley, J., T. Waidmann, S. Zuckerman, and R. A. Berenson	Health Services Research	46	5	1333-1361
Predictors of the Highest Long-Term Care Expenditures in Japan	2011	Olivares-Tirado, P., N. Tamiya, M. Kashiwagi, and K. Kashiwagi	Health Services Research	11	103	1-13
Free to Die	2011	P. Krugman	New York Times	9/15/2011		
Futility, Autonomy, and Cost in End-of-Life Care	2011	M. Baily	Journal of Law, Medicine & Ethics	39	2	172-182
Caring for the Seriously Ill: Cost and Public Policy	2011	Pope, T. M., R. M., Arnold and A. E. Barnato	Journal of Law, Medicine & Ethics	39	2	111-113
The Cost of Hope	2012	A. Bennett	Newsweek	6/4/2012		
<i>Subject/Category: Critical care</i>						
The Most Influential Articles in Critical Care Medicine	2010	Rosenberg, A. L., R. S. Tripathi, and J. Blum	Journal of Critical Care	25	1	157-170
<i>Subject/Category: Emergency care</i>						
The Geriatric Emergency Department	2007	Hwang, U. and R. S. Morrison	Journal of the American Geriatric Society	55	11	1873-1876
For the Elderly, Emergency Rooms of Their Own	2012	A. Hartocollis	New York Times	4/9/2012		
<i>Subject/Category: End-of-life care</i>						
Promoting Excellence in End-of-Life Care: A Report on Innovative Models of Palliative Care	2006	Byock, I., J. S. Twohig, M. Merriman, and K. Collins	Journal of Palliative Medicine	9	1	137-151
Surgery Rate Late in Life Surprises Researchers	2011	G. Kolata	New York Times	10/5/2011		
<i>Subject/Category: End-of-life definition</i>						
NIH State-of-the-Science Conference Statement on Improving End-of-Life Care	2004	National Institutes of Health	NIH Consensus and State-of-the-Science Statements	21	3	1-32
Overview of the Domains of Variables Relevant to End-of-Life Care	2005	Ferrell, B. R.	Journal of Palliative Medicine	8	Supp. 1	S22-S29

Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/ Category: End-of-life definition (con't)</i>						
Optimal Approaches to the Health Economics of Palliative Care: Report of an International Think Tank	2009	Gomes, B., R. Harding, K. M. Foley, and I. J. Higginson	Journal of Pain and Symptom Management	38	1	4-10
<i>Subject/ Category: End-of-life patient assessment</i>						
Prediction of Survival of Patients Terminally Ill with Cancer: Results of an Italian Prospective Multicentric Study	1995	Maltoni, M., Pirovano, M., Scarpi, E., Marinari, M., Indelli, M., Arnoldi, E., Gallucci, M., Frontini, L., L. Piva and D. Amadori	Cancer	75	10	2613-2622
Quality of Life in Oncology Practice: A Prognostic Value of EORTC QLQ-C30 Scores in Patients with Advanced Malignancy	1997	Coates, A., F. Porzsolt and D. Osoba	European Journal of Cancer	33	7	1025-1030
<i>Subject/ Category: End-of-life preferences</i>						
Are Regional Variations in End-of-Life Care Intensity Explained by Patient Preferences?	2007	Barnato, A. E., M. B. Herndon, D. L. Anthony, P. M. Gallagher, J. S. Skinner, J. P. W. Bynum, and E. S. Fisher	Med Care	45	5	386-393
The Default Effect in End-of-Life Medical Treatment Preferences	2007	Kressel, L. M. and G. B. Chapman	Medical Decision Making	27	3	299-310
Proximity to Death and Participation in the Long-Term Care Market	2009	Weaver, F., S. C. Stearns, E. C. Norton, and W. Spector	Health Economics	18	8	867-883
Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer	2010	Temel, J. S., J. A. Greer, A. Muzikansky, E. R. Gallagher, S. Admane, V. A. Jackson, C. M. Dahlin, C. D. Blinderman, J. Jacobsen, W. F. Pirl, J. A. Billings, and T. J. Lynch	New England Journal of Medicine	363	8	733-742
Physician Factors Associated with Discussions about End-of-Life Care	2010	Keating, N. L., M. B. Landrum, S. O. Rogers Jr., S. K. Baum, B. A. Virnig, H. A. Huskamp, C. C. Earle, and K. L. Kahn.	Cancer	116	4	998-1006
The Evolution of Advance Directives	2011	White, D. B. and R. M. Arnold	Journal of the American Medical Association	306	13	1485-1486
End-of-Life Decision Making across Cultures	2011	R. H. Blank	Journal of Law, Medicine & Ethics	39	2	201-214

Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/Category: End-of-life preferences (con't)</i>						
Knowing Loved Ones' End-of-Life Health Care Wishes: Attachment Security Predicts Caregivers' Accuracy	2011	Turan, B., Goldstein, M. K., A. M. Garber and L. L. Carstensen	Health Psychology	30	6	814-818
<i>Subject/Category: English experience</i>						
End of Life Care Strategy – Promoting High Quality Care for all Adults at the End of Life	2008	Traue, D., Graham-Brown, R., Pugh, E., Levy, D., Roland, M., Toovey, J., Warin, W., Douglas, I., Omany, J., Tate, T., J. Ellershaw and R. George	Department of Health (England)			1-171
Funding the Right Care and Support for Everyone: Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review	2011	Hughes-Hallett, T., A. Craft, C. Davies, I. Mackay, T. Nielsson	Palliative Care Funding Review	07/2011		1-99
<i>Subject/Category: Ethics</i>						
Palliative Care Research: Trading Ethics for an Evidence Base	2002	Jubb, A. M.	Journal of Medical Ethics	28	6	342-346
The Importance of Age in Allocating Health Care Resources: Does Intervention-Type Matter?	2005	Johri, M., L. J. Damschroder, B. J. Zikmund-Fisher, and P. A. Ubel	Health Economics	14	7	669-678
Economic and Policy Implications of Improving Longevity	2005	Vladeck, V. C.	Journal of the American Geriatric Society	53	9	S304-S307
Palliative Care: The Public Health Strategy	2007	Stjernsward, J.	Journal of Public Health Policy	28	1	42-55
Patient and Surrogate Disagreement in End-of-Life Decisions: Can Surrogates Accurately Predict Patients' Preferences?	2008	Marks, M. A. Z. and H. A. Arkes	Medical Decision Making	28	4	524-531
Improving Decision Making at the End of Life With Video Images	2010	Volandes, A. E., M. J. Barry, Y. Chang, and M. K. Paasche-Orlow	Medical Decision Making	30	1	29-34
The Palliative Care Information Act in Real Life	2011	Astrow, A. B. and B. Popp	New England Journal of Medicine	364	20	1885-1887
End-of-Life Care: A Philosophical or Management Problem?	2011	D. Callahan	Journal of Law, Medicine & Ethics	39	2	114-120
The Value of Life at the End of Life: A Critical Assessment of Hope and Other Factors	2011	P. T. Menzel	Journal of Law, Medicine & Ethics	39	2	215-223
Health Care Costs in End-of-Life and Palliative Care: The Quest for Ethical Reform	2011	Jennings, B. and M. B. Morrissey	Journal of Social Work in End-of-Life & Palliative Care	7	4	300-317
<i>Subject/Category: Financing</i>						
End-of-Life Medical Treatment Choices: Do Survival Chances and Out-of-Pocket Costs Matter?	2008	Chao, L., J. A. Pagan, and B. J. Soldo	Medical Decision Making	28	4	511-523

Article Title	Year	Author(s)	Journal/Source	Volume	Issue	Pages
<i>Subject/Category: Government procedure</i>						
Multiple Chronic Conditions: A Strategic Framework	2010	U.S. Department of Health & Human Services	U.S. Department of Health & Human Services	12/2010		1-18
<i>Subject/Category: Healthcare access</i>						
Predictive Modeling: A Guide for State Medicaid Purchasers	2009	Knutson, D., M. Bella, and K. Llanos.	Center for Health Care Strategies, Inc.	08/2009		1-38
<i>Subject/Category: Medical training</i>						
End-of-Life Training in U.S. Medical Schools: A Systematic Literature Review	2007	Bickel-Swenson, D.	Journal of Palliative Medicine	10	1	229-235
<i>Subject/Category: Procedure</i>						
NASW Standards for Palliative & End of Life Care	2004	National Association of Social Workers	National Association of Social Workers			1-36
<i>Subject/Category: Public policy</i>						
Just Caring: Health Care Rationing, Terminal Illness, and the Medically Least Well Off	2011	L. M. Fleck	Journal of Law, Medicine & Ethics	39	2	156-171
<i>Subject/Category: Research design</i>						
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