## Turning data into information to improve patient care

**HOSPICE ANALYTICS** 

Hospice Analytics is an information-sharing research organization whose mission is to improve hospice utilization and access to quality end-of-life care through analysis of Medicare and other national datasets. Please contact Hospice Analytics with any questions or ways we may assist you.

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# Physician Referrals: If It's Medicare Data, It's Illegal; If It Isn't Medicare Data, It's Irrelevant

Think how helpful it would be to use Medicare claims to identify specific people. We could use Social Security Numbers to link individual's diagnoses and health utilization patterns to their addresses, income, and education levels. We could even use National Provider Identifiers to link to an individual physician's patient base, prescribing preferences, and referral patterns. We could link SSN and NPI databases to reveal a shocking level of detail about every person touching health care in any way.

There's just one problem — *it's illegal.* Medicare never intended those working with its claims to identify specific people, beneficiaries or physicians. Quite the opposite; Medicare requires all who work with claims data to sign a Data Use Agreement that includes the following: *The User shall not attempt to identify or contact any specific individual whose record is included in the limited data set files.* 

Faith Asper, Director of Assistance at the Research Data Assistance Center (a CMS contractor providing technical assistance to those working with Medicare data), concurs, noting that unencrypting the NPI is not allowed under the Data Use Agreement. Maribel Franey, CMS Director of the Privacy Policy Compliance Group, adds that any organization engaging in activities violating the Data Use Agreement could jeopardize their access to future Medicare data.

However, some companies have figured out how to convert the de-identified NPI field in Medicare claims into actual NPI numbers, and then describe specific referral patterns of identified physicians. While such information may be useful to hospice providers, please consider the source, as well as the ethical and legal violations that occurred to provide this information. Please consider the potential for violating other standards - for example, patient confidentiality - if you choose to support companies violating physician confidentiality. To report organizations potentially violating CMS' Data Use Agreement, please contact the DHHS Office of the Inspector General at 800-447-8477. With 85% - 90% of hospice patients being Medicare beneficiaries, physician referral information that isn't Medicare is irrelevant to hospice. Bottom line: Please help keep the hospice industry above reproach, avoid physician referral information based on Medicare claims files.

### **Racial Diversity Among Hospice Beneficiaries**

How diverse are Medicare Hospice beneficiaries? In Hawaii, 68% of 2010 Medicare beneficiaries who died in hospice were minorities, and minorities accounted for 60% of District of Columbia and 21% of Louisiana and Mississippi hospice beneficiary deaths, respectively. The national average of minorities served by hospices is 11%.

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## Older Adults Not Enrolled in Hospice Have High Rates of Emergency Department Use in the Last Month of Life

Most patients are subsequently admitted to the hospital, where many die

More than half of older Americans in the final month of life seek medical help from an emergency department, where the focus is on stabilization and triage, not end-of-life care. Thus, more than three-quarters of these patients are admitted to an acute care facility, and more than two-thirds spend their final days there, according to a report published in *Health Affairs*.

"Emergency departments are not designed to provide endof-life care and in many ways are poorly suited to doing so," write the authors, led by Alexander K. Smith, MD, MS, MPH, assistant professor of medicine in the Division of Geriatrics at the University of California, San Francisco.

"Early enrollment in hospice [i.e., enrollment prior to the last month of life] was the strongest predictor of lack of emergency department use," the authors continue. "In our study, early enrollment was associated with 80% less use of the emergency department in the last month of life, and dramatically reduced rates of hospitalization and of death in the hospital, compared to the rates for patients who did not enroll early."

Researchers analyzed the health records of 4158 persons aged 65 years and older (mean age, 83 years; female, 47%) who died between 1992 and 2006. Data were drawn from the nationally representative Health and Retirement Study and linked with data from Medicare claims.

#### DECEDENT CHARACTERISTICS

- Mean number of chronic diseases was 1.4 (out of four: heart condition, cancer, stroke, and lung disease).
- 77% of patients were dependent in at least one activity of daily living; 67% were dependent in three or more activities of daily living.
- 57% of patients had a heart condition; 31% had cancer.
- 43% were cognitively impaired.
- 46% experienced moderate to severe pain.
- Only 9% were enrolled in hospice for longer than one month prior to death.

Many of the symptoms that lead patients to visit the emergency department — such as pain, shortness of breath, and confusion — are common among those nearing the end of life, and are the very symptoms that hospice professionals are trained to manage, point out the authors.

#### USE OF EMERGENCY MEDICAL SERVICES

• 51% of decedents visited the emergency department in the last month of life; 75%, in the last six months of life.

"The type of care that patients receive in hospice...is of benefit long before the final days of life."

-Smith et al, Health Affairs

- 77% of those visiting the emergency department in the last month of life were admitted to the hospital.
- Of those patients admitted in the last month of life, 68% died while hospitalized.
- 39% of those hospitalized in the last month of life were admitted to an intensive care unit.
- Repeat visits to the emergency department were common: 41% of decedents made more than one visit in the last six months of life, and 12% visited the emergency department more than once in the last month of life.

The rates of end-of-life hospitalization are unlikely to decrease without a decrease in the rates of emergency department use, note the authors. "Many health problems and symptoms in late life are predictable, and some visits to the emergency department could potentially be avoided with access to highquality outpatient care."

#### PHYSICIANS IN AN OUTPATIENT SETTING CAN:

- Prepare older patients and their families for end-of-life symptoms that may occur.
- Engage in ongoing discussions about goals of care.
- Arrange for treatment aligned with the patient's values and wishes.
- Document patient preferences in a way that is easily accessible to other providers.

"For patients whose terminal trajectories are clear, we can do better in the outpatient setting," observe the authors. "Outpatient providers can help prepare families for the eventuality of death, including by giving them early referrals to hospice and, where available, to outpatient palliative care services." In addition, the authors recommend that "policies that require physicians to disclose a terminal prognosis and that provide reimbursement for advance care planning should be encouraged."

Source: "Half of Older Americans Seen in Emergency Department in Last Month of Life; Most Admitted to Hospital, and Many Die There," Health Affairs; June 2012; 31(6):1277-1285. Smith AK, McCarthy E, Weber E, Cenzer IS, Boscardin J, Fisher J, Covinsky K; Division of Geriatrics, Department of Medicine; and Department of Emergency Medicine, University of California, San Francisco; Departments of Medicine and Emergency Medicine, Harvard Medical School, Boston.

## Study Identifies Factors Linked to Better Quality of Life at End of Life

Previous research has provided data on end-of-life (EOL) factors considered important by physicians, patients, and caregivers, and on factors that predict quality care at the EOL, but few data exist on what predicts better quality of life (QOL) at the EOL for patients dying of cancer, according to a report published in the *Archives of Internal Medicine*.

"The aim of this study was to identify the best set of predictors of QOL of patients in their final week of life," write lead author Baohui Zhang, MS, formerly of the Dana-Farber Cancer Institute in Boston, and colleagues. "By doing so, we identify promising targets for health care interventions to improve the QOL of dying patients."

Investigators conducted a multi-site, prospective, longitudinal study of 396 patients with advanced cancer (mean age, 58.7 years; white race, 65.0%) and their informal caregivers, as part of the federally funded Coping with Cancer study. Patients with an estimated life expectancy of less than six months were followed from their enrollment (from 2002 to 2008) to death, a median of 4.1 months later.

The team identified a set of nine factors that explained the most variance in patients' QOL at the EOL. Only one factor, site of cancer care, had random effects on QOL, while the majority of the variance in QOL remained unexplained.

#### **NEGATIVE IMPACT ON QOL**

Factors with a negative impact on QOL at the EOL included:

- Intensive care unit (ICU) stays in the final week of life (explained 4.4% of the variance in QOL)
- Hospital deaths (2.7%)
- Patient worry at baseline (2.7%)
- Feeding tube use in the final week (1.1%)
- Chemotherapy in the final week (0.8%)

"Two of the most important determinants of poor patient QOL at the EOL were dying in a hospital and ICU stays in the last week of life," write the authors. "Therefore, attempts to avoid costly hospitalizations and to encourage transfer of hospitalized patients to home or hospice might improve patient quality of life at the end of life."

#### POSITIVE IMPACT ON QOL

Factors with a positive effect on QOL included:

- Religious prayer or meditation at baseline (2.5%)
- Pastoral care within the hospital or clinic (1.0%)
- Patient-physician therapeutic alliance at baseline (0.7%)

A therapeutic alliance is a physician-patient relationship described by the patient as: being seen by the physician as a whole person; being treated with respect; respecting and trusting the physician; and feeling comfortable with asking the physician "By reducing patient worry, encouraging contemplation, integrating pastoral care within medical care, fostering a therapeutic alliance between patient and physician that enables patients to feel dignified, and preventing unnecessary hospitalizations and receipt of life-prolonging care, physicians can enable their patients to live their last days with the highest possible level of comfort and care."

- Zhang et al, Archives of Internal Medicine

questions about health care.

"These results suggest that physicians who are able to remain engaged and 'present' for their dying patients — by inviting and answering questions and by treating patients in a way that makes them feel that they matter as fellow human beings — have the capacity to improve a dying patient's QOL," comment the authors.

Suggested targets for health care interventions to improve QOL include:

- Limiting aggressive EOL treatments such as chemotherapy and the use of feeding tubes
- · Avoiding unnecessary hospitalizations
- Encouraging the transfer of hospitalized patients to home or hospice
- Reducing patient anxiety
- Supporting patient spirituality and peacefulness, and encouraging the use of pastoral services

"Taken together, these results indicate that when medicine is no longer able to cure, physicians may still positively and significantly influence the lives of their patients," the authors conclude. "By establishing empirically the strongest set of predictors of QOL at the EOL for terminally ill advanced cancer patients, we can guide physicians, patients, and family members in focusing on what matters most for ensuring a high QOL for dying cancer patients."

The study was published in the online first edition of the *Archives of Internal Medicine* as part of a large group of articles focused on improving QOL at the EOL. The journal has also scheduled articles on this theme for publication in its August 13/27, 2012, print issue.

Source: "Factors Important to Patients' Quality of Life at the End of Life," Archives of Internal Medicine; Epub ahead of print, July 9, 2012; DOI: 10.1001/ archinternmed.2012.2364. Zhang B, Nilsson ME, Prigerson HG; Center for Psychosocial Epidemiology and Outcomes Research and Division of Population Sciences, Department of Medical Oncology, Dana-Farber Cancer Institute; and Department of Psychiatry, Brigham and Women's Hospital, Harvard Medical School, Boston.

## Racial Diversity Among Hospice Beneficiaries (continued)

The top ten states for minority deaths in hospice include: \*

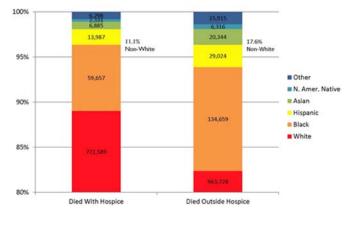
STATE	DIED WITH HOSPICE	DIED WITHOUT HOSPICE	DIFFERENCE
1. HI	68%	73%	5%
2. DC	60%	79%	19%
3. LA	21%	31%	10%
4. MS	21%	33%	12%
5. MD	20%	29%	9%
6. GA	19%	29%	10%
7. SC	18%	29%	11%
8. AL	17%	24%	7%
9. CA	15%	27%	12%
10. NC	15%	23%	8%

\* Please contact Hospice Analytics for similar information on your state.

Interestingly, Medicare minority deaths outside of hospice account for nearly 18% of beneficiaries, although hospices on average serve only 11%; a significant difference of 7%. Hawaii fairs well in this regard, with minority deaths outside of hospice accounting for 73% of Medicare beneficiary deaths while serving 68% minorities in hospice; a smaller difference of 5%. District of Columbia was worse than the national average, with 79% minority deaths outside of hospice and 60% minority deaths in hospice; a substantial difference of 19%. Only one state, Wyoming, had a higher percentage of minority deaths with hospice, compared to minority deaths without hospice.

Jamey Boudreaux, Executive Director of LMHPCO, comments that minority-owned hospices appear to have little difficulty enrolling minority patients. Dr. Cordt Kassner observes a direct correlation between the percentage of minority staff and the percentage of minority patients based on discussions with hospice leaders across the country. While many hospices struggle with enrolling minorities and tend to blame cultural differences, other hospices appear to have figured it out. **Bottom line: Hospices with high percentages of minority patients are encouraged to share their experiences and best practices, as nationally it appears there is room for improvement.** 

#### Race Among 2010 Medicare Beneficiaries



## **NEVER underestimate the POWER of data...**

Hospice Analytics is an information-sharing organization whose mission is to improve hospice utilization and access to quality end-of-life care through analysis of Medicare and other national datasets.

More than 50% of the State Hospice Organizations participate in Hospice Analytics' Market Reports Project. These State Hospice Organizations represent over 60% of the hospices serving over 70% of the hospice patients in the country.

Substantial revenue is shared with participating non-profit State Hospice Organizations.

For additional information, please contact:

719.209.1237

Cordt T. Kassner, PhD CKassner@HospiceAnalytics.com

