

How Many Nursing Home Residents Live With a Mental Illness?

Ann D. Bagchi, Ph.D.
James M. Verdier, J.D.
Samuel E. Simon, Ph.D.

Objective: A number of data sets can be used to estimate the size of the nursing home population that has mental illness; however, estimates vary because of differences in methods of data collection. This study sought to compare estimates from three nationally representative data sets of the number of nursing home residents who have a mental illness, determine which data set provides the best national-level estimate, and identify the types of policy and monitoring questions that can best be answered with each. **Methods:** The study compared estimates of the number of nursing home residents who had either a primary or any diagnosed mental illness from the National Nursing Home Survey (NNHS), the Minimum Data Set (MDS), and the Medicaid Analytic eXtract (MAX) files. **Results:** The NNHS produced the most valid national-level estimates of residents with a mental illness—nearly 102,000 with a primary diagnosis in 2004 (6.8% of residents), of which about 23,000 were under age 65 and 79,000 were aged 65 and older. However, data from the NNHS cannot be broken down to the state level; therefore, state- and facility-level estimates would have to be generated with the MDS or MAX data sets. **Conclusions:** Policy makers and program managers need to be aware of the strengths and limitations of the data they use in order to make informed decisions. Users of the NNHS, MDS, and MAX data sets should be aware of the differences in recorded diagnoses among the three, especially the relatively limited diagnoses in the MAX and imprecise diagnoses in the MDS. (*Psychiatric Services* 60:958–964, 2009)

Congress passed the nursing home reform provisions of the 1987 Omnibus Budget Reconciliation Act (OBRA-87) in response to a study by the Institute of Medicine that assessed the quality of care in nursing homes (1). One requirement stipulates that nursing home applicants receive preadmission screening for mental illness and mental retardation to identify the proper residential settings to accommodate their needs (2–4). The Centers for Medicare and Medicaid Services (CMS—at the time, the Health Care Financing Administration) de-

veloped what is now called Preadmission Screening and Resident Review (PASRR) as the interpretive guidelines regulating how states implement the preadmission requirements (5). The provisions state that individuals with mental illness should not be admitted to nursing facilities if they do not have other health care needs that require nursing services (4). For residents with both a mental illness and a need for nursing assistance, the regulations require that facilities provide active mental health treatment.

Since passage of OBRA-87, a limited number of studies have used dif-

ferent data sets to document the size of the mentally ill population of nursing facility residents and examine the care that these patients receive (6–8). Mechanic and McAlpine (7) analyzed the 1985 and 1995 National Nursing Home Survey (NNHS) and the 1987 and 1996 Medical Expenditure Survey (MES) to assess the initial impact of OBRA-87. The NNHS codes diagnoses on the basis of *ICD-9-CM*, whereas the MES includes indicators for a number of “active” mental disorders, including schizophrenia, bipolar disorder, depression, dementia or organic brain disorder, and anxiety. Mechanic and McAlpine excluded from their analyses residents with mental retardation but included all other residents with diagnoses corresponding to *ICD-9-CM* codes in the range 290–317. They found that 58% of residents in the 1995 NNHS versus 68% in the MES had a diagnosed mental disorder. In both cases, dementia and related disorders accounted for a large share of the recorded diagnoses (41% of residents in the NNHS and 50% in the MES).

A 2001 Office of the Inspector General report used 1998 Medicaid Statistical Information System records from 34 states and the 1999 Minimum Data Set (MDS) from 39 states to document the size of the nursing home population between ages 22 and 64 who had a mental illness (6). Although the report also used *ICD-9-CM* codes to identify residents who had mental disorders, the analyses were limited to a small range of diagnoses (codes 293–301, 311, and 312) and provided no prevalence estimates.

Shea and colleagues (8) used the

The authors are affiliated with Mathematica Policy Research, Inc., 600 Alexander Park, Princeton, NJ 08540 (e-mail: abagchi@mathematica-mpr.com).

Medicare Current Beneficiary Survey for 1992 and defined mental illness with the use of indicators for whether respondents had ever been told they had a mental illness or were receiving Medicare benefits because of disability caused by mental illness. Excluding residents with Alzheimer's disease, they found that 20% of the 732 nursing facility residents in their sample reported having a mental illness.

These studies demonstrated that data sets vary in their methods for identifying mental illness diagnoses, which can lead to vastly different estimates of the size of the nursing home population with mental illness. With this study we sought to build on those findings by identifying differences in estimates of the number of residents with a mental illness from three nationally representative data sets (the NNHS, the MDS, and CMS Medicaid Analytic eXtract [MAX] files), determining which of these data sets provides the best estimate of the size of the national population of nursing home residents with mental illness, and identifying the types of policy and monitoring questions that can best be answered with each data set.

Methods

Because the statutory definition of mental illness for PASRR specifically excludes persons with dementia and related conditions (if their primary diagnosis is not mental illness), and because individuals with mental retardation are treated separately under the screening and review process, our analyses excluded these diagnoses. We also excluded substance use disorders because our intention was to focus on the population with mental disorders. Preliminary analyses found that alcohol- and drug-induced mental disorders account for less than 2% of primary mental illness diagnoses among nursing home residents. Thus mental illness was defined in our study as conditions corresponding to *ICD-9-CM* codes ranging from 295 to 302 and from 306 to 314.

The NNHS is a nationally representative survey of certified and state-licensed nursing facilities conducted periodically by the National

Center for Health Statistics. The 1999 NNHS used a two-stage probability design that first sampled facilities with at least three beds and then identified six current residents and six residents who had been discharged within a designated month (9). Nursing facility staff provided surveyors with written descriptions of patients' illnesses at admission and at the time of survey administration as recorded in patients' medical records or the facility's MDS file. These descriptions were later assigned *ICD-9-CM* codes by an independent vendor.

The MAX files represent the more than 65% of nursing facility residents whose care is paid for by Medicaid. Analyses for this study included all types of facilities except inpatient psychiatric services for individuals aged 21 and under and intermediate-care facility services for persons with mental retardation. Each claim in the MAX long-term-care files may include up to five diagnoses, reported as *ICD-9-CM* codes. However, analysis of the 1999 files found that 42.5% had no valid diagnosis code; another 30.7% had only one, and the remaining 26.8% had two or more valid codes (71.5% of these records had only two codes; the remaining had three or more). Among cases with a valid code, the diagnoses listed often are the original admitting diagnoses rather than the most current. In order to improve the identification of relevant diagnoses and to ensure greater comparability between the findings from the MAX, MDS, and NNHS, our analysis included mental illness diagnoses from the inpatient and outpatient Medicaid claims in the MAX files. Inpatient claims were included if they occurred after the date of the long-term-care claim, and outpatient claims were included if they occurred in the same month as the long-term-care claim. Studies that examined the reliability of Medicaid claims data for use in research on psychiatric disorders have found the primary and secondary diagnosis variables to be reliable (10,11).

All long-term-care facilities that are certified to participate in Medicare or Medicaid are required to complete the MDS for all residents

at the time of their admission and at least quarterly thereafter. The MDS includes two ways to record diagnoses. The staff member filling out the form can either mark checkboxes for specific physician-documented diagnoses (including schizophrenia, depression, bipolar disorder, and anxiety disorder) or record up to five conditions by their *ICD-9-CM* codes in a separate space on the form. It is not possible to determine a patient's primary diagnosis with the MDS because the staff member recording diagnoses is not required to list them in any particular order. Reliability estimates indicate that the psychiatric and mood diagnostic items in the MDS have an average kappa (a statistic that compares the agreement between raters, where 1.0 is perfect agreement) of .83. Kappa ranged from .79 for anxiety disorder to .85 for bipolar disorder (12-14).

As detailed in Table 1, each of the data sets evaluated has strengths and weaknesses for policy analysis. Given the methodological variations in the data sets, several modifications were necessary to create more comparable analytic files. First, we used data from 1999 because this was the most recent year for which research-ready data were available for all three data sources at the time of writing. Second, we restricted the MDS to residents who had either an admission or an annual assessment in the latter half of the year, because that is the period covered by the NNHS. We restricted the MAX to residents with a claim during the same period. Finally, we restricted the NNHS and MDS files to residents for whom Medicaid was the primary or a secondary payer (to match the payer status of residents represented in the MAX). Limiting the data to residents with Medicaid-covered expenses improved the comparability of the data files for analysis but also limited the generalizability of our findings to the national population of nursing home residents. Residents excluded because of the Medicaid restriction (about 10% in the MDS and 25% in the NNHS) were less likely to have a diagnosis of mental illness than those included in the study sample. Those in the excluded group with a diagnosis of

Table 1

Strengths and limitations of nationally representative data sets pertaining to nursing home residents

| Data set and file description | Strengths | Limitations |
|--|---|---|
| National Nursing Home Survey Nationally representative survey of certified and state-licensed nursing facilities Mental illnesses are identified through descriptions of diagnoses that are converted to <i>ICD-9-CM</i> codes Data are collected by survey field staff | Nationally representative of all nursing facilities; includes certified ^a and state-licensed facilities; public use files can be obtained from NCHS ^b Web site; includes detailed <i>ICD-9-CM</i> codes; includes primary and secondary diagnosis codes; can link resident and facility files at the NCHS Research Data Center | Estimates are reliable only at the national level; survey is conducted intermittently so it cannot be used to explore yearly longitudinal patterns; cannot link the files to other data sets; pre-2004 files do not include data on medications or drug expenditures; diagnoses are based on descriptions that are converted to <i>ICD-9-CM</i> codes; data are representative only of those in residence in the latter half of the year |
| Medicaid Analytic eXtract Aggregate of all Medicaid-paid claims for nursing home residents Mental illnesses are identified through <i>ICD-9-CM</i> codes reported in claims Data are reported by state Medicaid agencies for all billable services | Includes all services paid by Medicaid; can be linked to other federal data sources (such as Medicare claims); includes complete Medicaid drug claims; data are standardized across states as of 1999; data are available annually for all states; diagnoses are based on <i>ICD-9-CM</i> codes recorded in claims; file includes date of death | Includes only residents with Medicaid-paid claims; data-processing of claims creates 2-year delay in data availability; diagnoses are limited in the long-term-care file and are not updated regularly; data are provided at the claim level and require programming to create individual- or facility-level files; data are limited to paid claims and do not include other services not paid by Medicaid; obtaining data requires data use agreement; there is a charge to obtain the files |
| Minimum Data Set Resident assessment instrument completed for all residents at the time of their admission and at least quarterly thereafter within long-term-care facilities that are certified to participate in Medicare or Medicaid Mental illnesses are defined primarily through checkboxes for specific conditions, but data also include some diagnoses based on <i>ICD-9-CM</i> codes Data reported by nursing facility staff | Includes all certified facilities; can link the data to other federal data sources; data are available annually and for all states; it is possible to conduct resident- and facility-level analyses; CMS ^c usually provides state-level summary data within 3 months of data entry by nursing facility staff; diagnostic data are regularly updated; captures clinical, functional, behavioral, and emotional status conditions; provides the most complete data on race and ethnicity of nursing facility residents; data are collected at mandated intervals | Excludes facilities with only state licensure; involves a lengthy process to obtain files; there is a charge to obtain files; contains limited information on drug use; data before October 1998 are of poor quality; diagnoses derived from checkboxes on a form may be less reliable than those based on <i>ICD-9-CM</i> codes; it is impossible to identify the primary diagnosis from the data; data are provided at the assessment level and require programming to create individual- or facility-level files |

^a Nursing homes that are certified by Medicare or Medicaid as being in compliance with the requirements in 42 CFR Part 483, Subpart B

^b NCHS, National Center for Health Statistics

^c Centers for Medicare and Medicaid Services

mental illness were less likely to have a diagnosis of schizophrenia and were more likely to have depression. Demographically, residents excluded from the analyses were older and more likely to be white than residents in the study subpopulation.

The analyses distinguish between primary diagnoses of mental illness and any diagnosed mental illness. In the NNHS and the MAX, the primary diagnosis is the first listed diagnosis code; residents were counted as having any mental illness diagnosis if at least one of the remaining diagnosis variables contained an *ICD-9-CM* code within the specified range (specifically, 295–302 and 306–314). Because it is impossible to identify a res-

ident's primary diagnosis with the MDS, we focused the analyses on residents with any mental illness diagnosis (defined as those for whom schizophrenia, depression, anxiety, or bipolar disorder was indicated on the checkboxes or for whom any of the "other diagnosis" variables included the specified *ICD-9-CM* codes). Therefore, we were able to compare the NNHS and MAX by primary diagnosis and to compare all three data sets for any mental illness diagnosis.

Results

Limiting the MDS and MAX to the population of residents in the facility in the last half of the year reduced the number of residents represented in

the MDS to 51.8% of the original total and that of the MAX to just under 83.0% of the original (Table 2). The disproportionate drop in the number of residents from the MDS compared with the MAX likely reflects sampling bias; the MDS is based on only annual and admission assessments (either of which should occur once in the year), whereas MAX includes all residents with a claim (which could occur multiple times across the entire year). Restricting each of the data sets by Medicaid payer reduced the NNHS to 63.1% of the original number of residents and left the MDS with less than a quarter of the original number of residents. However, the distribution of residents by demographic

Table 2

Size of nursing home resident population after introduction of restrictions for time of residence and payer type, by 1999 data set

| Restriction | National Nursing Home Survey | | Minimum Data Set | | Medicaid Analytic eXtract | |
|--|------------------------------|-------|------------------|-------|---------------------------|-------|
| | N | % | N | % | N | % |
| None: total number of residents represented in the data set ^a | 1,628,265 | 100.0 | 2,311,399 | 100.0 | 1,509,448 | 100.0 |
| Persons resident between July 1 and December 31, 1999 ^b | 1,628,265 | 100.0 | 1,196,311 | 51.8 | 1,247,055 | 82.6 |
| Persons resident between July 1 and December 31, 1999, and with Medicaid as payer ^c | 1,028,067 | 63.1 | 489,294 | 21.2 | 1,247,055 | 82.6 |

^a For the National Nursing Home Survey, the total represents the unduplicated, weighted number of residents represented in the 1999 survey. The actual number of residents interviewed for the survey was 8,215. The results for those residents were weighted and extrapolated in order to represent the total nursing home population. The total for the Minimum Data Set is the unduplicated number of residents with any admission or annual assessment in 1999 (including all lengths of stay). For the Medicaid Analytic eXtract, the total is the unduplicated number of nursing home residents with any Medicaid-paid claims in 1999.

^b Because facilities were sampled for the National Nursing Home Survey only between July 1 and December 31, 1999, limiting the inclusion criteria to persons who were residents in the latter half of the year did not change the number of residents represented in the data set.

^c Either primary or secondary payer. Because the Medicaid Analytic eXtract includes only the claims paid by Medicaid, limiting the inclusion criteria to residents with Medicaid as payer did not change the number of residents represented in the data set.

characteristics was quite similar across data sets even after introducing these restrictions (Table 3). Although the differences were statistically significant with the large file sizes, there were few meaningful differences by demographic subgroup; a majority of residents in all three data sets were white women of age 75 or older.

Table 4 highlights significant variations in the prevalence of mental illness for all residents and by age group, 64 or younger versus 65 or older (because of space limitations, standard errors are not reported in Tables 4 and 5 but are available from the authors on request). Within the NNHS, 7.0% of the entire nursing home population had a primary diag-

nosis of mental illness, compared with 4.3% in the MAX. By comparison, although 33.1% of residents in the NNHS had any mental illness diagnosis, the percentage was much lower in the MAX (at only 18.3%) but larger in the MDS (46.0%). Across all three data sets, a majority of residents with any diagnosed mental disorder had only one diagnosis of mental ill-

Table 3

Population characteristics within a comparative subset of nursing home residents, by 1999 data set^a

| Characteristic | National Nursing Home Survey (N=1,028,067) | | | Minimum Data Set (N=489,294) | | | Medicaid Analytic eXtract (N=1,247,055) | | |
|------------------|---|------|-------------------|---------------------------------|------|-------------------|--|------|-------------------|
| | N | % | SE % ^b | N | % | SE % ^b | N | % | SE % ^b |
| Age | | | | | | | | | |
| 0–20 | 1,998 | .2 | .063 | 2,248 | .5 | .143 | 4,115 | .3 | .089 |
| 21–44 | 24,750 | 2.4 | .219 | 19,112 | 3.9 | .140 | 39,537 | 3.2 | .088 |
| 45–64 | 99,551 | 9.7 | .422 | 58,698 | 12.0 | .134 | 125,548 | 10.1 | .085 |
| 65–74 | 140,609 | 13.7 | .490 | 70,921 | 14.5 | .132 | 175,878 | 14.1 | .083 |
| 75–84 | 323,741 | 31.5 | .663 | 150,846 | 30.8 | .119 | 393,909 | 31.6 | .074 |
| ≥85 | 437,418 | 42.6 | .705 | 187,187 | 38.3 | .112 | 504,318 | 40.4 | .069 |
| Data missing | 0 | — | — | 282 | .1 | .143 | 3,750 | .3 | .089 |
| Gender | | | | | | | | | |
| Female | 741,177 | 72.1 | .640 | 349,448 | 71.4 | .076 | 889,881 | 71.4 | .048 |
| Male | 286,890 | 27.9 | .640 | 139,707 | 28.6 | .121 | 353,487 | 28.4 | .076 |
| Data missing | 0 | — | — | 139 | .0 | .143 | 3,687 | .3 | .089 |
| Ethnicity | | | | | | | | | |
| White | 819,199 | 79.7 | .574 | 383,093 | 78.3 | .067 | 950,132 | 76.2 | .044 |
| African American | 144,614 | 14.1 | .496 | 73,676 | 15.1 | .132 | 159,628 | 12.8 | .084 |
| Other | 59,297 | 5.8 | .333 | 31,730 | 6.5 | .138 | 46,302 | 3.7 | .088 |
| Data missing | 4,957 | .5 | .099 | 795 | .2 | .143 | 90,993 | 7.3 | .086 |

^a Includes a sample of individuals who were residents between July 1 and December 31, 1999, and who had Medicaid as primary or secondary payer

^b Standard errors of the percentages were calculated differently for estimates from the National Nursing Home Survey than for the Minimum Data Set and the Medicaid Analytic eXtract. As a result of the sampling procedure for the National Nursing Home Survey, it was necessary to first calculate the relative standard error (9).

Table 4Population of nursing home residents with a diagnosed mental illness, by 1999 data set^a

| Population and diagnosis group | National Nursing Home Survey | | Minimum Data Set | | Medicaid Analytic eXtract | |
|---|------------------------------|-------|------------------|-------|---------------------------|-------|
| | N | % | N ^b | % | N ^b | % |
| Total population of residents | 1,028,067 | 100.0 | 489,294 | 100.0 | 1,247,055 | 100.0 |
| Primary diagnosis of a mental illness | 71,458 | 7.0 | na | na | 54,242 | 4.3 |
| Any diagnosis of a mental illness | 339,997 | 33.1 | 224,856 | 46.0 | 228,574 | 18.3 |
| Total population of residents aged 64 or younger ^c | 126,299 | 12.3 | 80,058 | 16.4 | 169,200 | 13.6 |
| Primary diagnosis of mental illness ^d | 18,666 | 14.8 | na | na | 15,879 | 9.4 |
| Any diagnosis of mental illness ^d | 55,691 | 44.1 | 40,358 | 50.4 | 57,831 | 34.2 |
| Total population of residents aged 65 or older ^c | 901,768 | 87.7 | 408,954 | 83.6 | 1,074,105 | 86.1 |
| Primary diagnosis of mental illness ^d | 52,792 | 5.8 | na | na | 38,293 | 3.6 |
| Any diagnosis of mental illness ^d | 284,306 | 31.5 | 184,404 | 45.1 | 170,488 | 15.9 |

^a Includes a sample of individuals who were residents between July 1 and December 31, 1999, and who had Medicaid as primary or secondary payer^b Age groups do not sum to total due to a small number of residents with missing values on age.^c Percentages were calculated from total number of residents.^d Percentages were calculated from age group subtotals.

ness (84.0% in the NNHS, 72.0% in the MDS, and 94.0% in the MAX; data not presented).

In both the NNHS and the MAX,

the percentage of younger residents with a primary diagnosis of mental illness was nearly three times that among older residents (for example,

in the NNHS, the proportions were 14.8% for residents aged 64 or younger and 5.1% for residents aged 65 or older). The prevalence of any

Table 5Percentage distribution of diagnoses for residents with primary or any diagnosed mental illness, by 1999 data set^a

| ICD-9-CM code | Diagnosis | Primary diagnosis ^b | | Any diagnosis | | |
|---------------|--|---|--------------------------------------|--|---|---|
| | | National Nursing Home Survey (N=71,458) | Medicaid Analytic eXtract (N=54,242) | National Nursing Home Survey (N=400,266 ^d) | Medicaid Analytic eXtract (N=290,754 ^d) | Minimum Data Set ^c (N=245,676 ^d) |
| 295 | Schizophrenia disorders | 39.0 | 33.4 | 13.8 | 18.1 | 13.0 |
| 296 | Affective psychoses | 11.4 | 9.8 | 6.8 | 18.1 | 4.4 |
| 297 | Paranoid states and delusional disorders | 1.6 | 1.1 | 2.7 | 1.5 | <.1 |
| 298 | Other nonorganic psychoses | 7.7 | 20.9 | 8.2 | 13.5 | <.1 |
| 299 | Psychoses with origin specific to childhood | <.1 | 1.4 | <.1 | .4 | <.1 |
| 300 | Neurotic disorders | 8.7 | 4.7 | 14.4 | 10.9 | 21.1 |
| 301 | Personality disorders | 1.6 | 1.0 | 1.6 | 1.8 | <.1 |
| 302 | Sexual deviations and disorders | <.1 | <.1 | .1 | .1 | <.1 |
| 306 | Physiological malfunction arising from mental factors | <.1 | .1 | .1 | .2 | <.1 |
| 307 | Special symptoms or syndromes, not elsewhere classified | .9 | .6 | 4.3 | 2.5 | <.1 |
| 308 | Acute reaction to stress | <.1 | <.1 | .1 | .3 | <.1 |
| 309 | Adjustment reaction | <.1 | .5 | .9 | 4.7 | <.1 |
| 310 | Specific nonpsychotic mental disorders from organic brain damage | 16.6 | 15.1 | 11.4 | 8.2 | <.1 |
| 311 | Depressive disorders, not elsewhere classified | 12.2 | 10.7 | 34.3 | 17.7 | 61.4 |
| 312 | Disturbance of conduct, not elsewhere classified | .3 | .4 | 1.4 | 1.9 | <.1 |
| 313 | Disturbance of emotions specific to childhood and adolescence | <.1 | .1 | <.1 | .1 | <.1 |
| 314 | Hyperkinetic syndrome of childhood | <.1 | .1 | <.1 | .1 | <.1 |

^a Includes a sample of individuals who were residents between July 1 and December 31, 1999, and who had Medicaid as primary or secondary payer^b Because primary diagnosis is not a meaningful designation in the Minimum Data Set, data are presented only for the National Nursing Home Survey and the Medicaid Analytic eXtract.^c Diagnoses from the Minimum Data Set checkboxes were assigned to ICD-9-CM codes as follows: schizophrenia was assigned to code 295, bipolar disorder to 296, anxiety disorder to 300, and depression to 311. The Minimum Data Set checkboxes do not distinguish between major depression (which would normally be assigned to code 296) and other depressive disorders (code 311); we chose to assign all Minimum Data Set depression diagnoses to code 311.^d Because some residents may have had more than one mental illness, the total represents the number of diagnoses, not an unduplicated count of residents.

mental illness diagnosis was more comparable across age groups but was still twice as large for younger versus older residents in the MAX (34.2% versus 15.9%, respectively).

Table 5 shows that the NNHS, MAX, and MDS data sets also varied significantly by recorded diagnosis. The distribution of *ICD-9-CM* codes for primary diagnoses was similar across the NNHS and MAX. There were similar percentages of the primary mental illness diagnoses identified in these data sets by code 295, schizophrenic disorders; 296, affective psychoses; 310, mental disorders resulting from brain damage; and 311, depressive disorders. However, a significantly higher percentage of residents in the MAX had a diagnosis of "other nonorganic psychoses" (code 298) (20.9% versus 7.7% in the NNHS), and a larger percentage of residents in the NNHS were diagnosed as having neurotic disorders (code 300) (8.7% versus 4.7% in the MAX).

The distribution of mental illness diagnoses was far less comparable in the case of any diagnosed mental illness. Most significantly, the four mental illness diagnoses captured with checkboxes in the MDS (that is, schizophrenia, bipolar disorder, anxiety disorder, and depression) accounted for nearly all mental illness diagnoses recorded in that data set. Although the prevalence of any diagnoses of schizophrenia disorders was similar between the NNHS and MDS (13.8% and 13.0%), it was higher in the MAX (18.1%). Similarly, although the NNHS and MDS indicated higher percentages of residents with diagnoses of a depressive disorder (34.3% and 61.4%, respectively) than the MAX indicated (17.7%), the percentage in the MDS was nearly twice that of the NNHS.

Because Medicare is the primary payer for residents who are also eligible for Medicaid and have stays less than 90 days and because Medicaid pays lower reimbursement rates, Medicaid may not be billed for mental health services for these short stays. As a result, diagnoses for these residents may be missed in the MAX claims. As a sensitivity test, we ran separate analyses with the NNHS and

MDS for short-stay residents (those with stays of 90 days or less). Although the prevalence rates of mental illness were slightly lower (46.0% versus 50.0% for any diagnosis in the MDS and 28.0% versus 33.0% in the NNHS), the distributions of diagnoses were similar.

Our review of the data suggests that because the NNHS included the most complete diagnostic information and was representative of the entire population of nursing home residents, it is the preferred data set from which to draw national prevalence estimates of the number of residents with a primary diagnosis of mental illness. In an analysis of the 2004 NNHS file (the year for which the most recent data were available), which included all residents and all payer types, we found that 101,667 (6.8%) of the 1.49 million nursing home residents represented in the data had a primary diagnosis of mental illness. The estimate was significantly higher among residents aged 65 or younger ($N=22,564$, 12.9%) and lower for those aged 65 or older ($N=79,038$, 6.0%). These estimates are similar to those for 1999 shown in Table 4.

Discussion

This study highlighted how discrepancies in the timing and methods of data collection for the NNHS, MDS, and MAX affect estimates of the number of nursing home residents with diagnosed mental illness as well as variations in the frequencies of specific diagnosis codes. The percentage of nursing home residents identified as having a primary mental illness was much lower in the MAX than in the NNHS, which may reflect the fact that 43.0% of the MAX claims were missing diagnosis codes in the long-term-care claims file. Because listing diagnoses in MAX does not directly affect nursing home payment, incentives to fully report diagnoses are limited.

Estimates of the percentage of residents with any diagnosed mental illness varied widely across data sets, at 33.1% in the NNHS compared with 46.0% in the MDS and 18.3% in the MAX. These estimates cannot be directly compared with estimates from

the literature because of differences in the methods used to record mental illness diagnoses, the subpopulations of nursing home residents included in the data sets chosen for analysis, and the specific diagnoses included for analysis. Our prevalence estimate from the NNHS was lower than that reported by Mechanic and McAlpine (7) because they included a wider range of diagnoses in their analyses. Not surprisingly, replicating their methodology with the 1999 NNHS yielded a similar prevalence estimate (53.0% in 1999 versus 58.0% in 1995).

The low estimate of mental illness from the MAX may reflect the fact that only 26.8% of nursing home residents had two or more diagnoses noted in their long-term-care claims (and the majority of these, 71.5%, had no more than two). The higher percentage seen in the MDS may reflect the fact that some nursing facility staff members use diagnoses as an aid in care planning, which may lead them to check all potentially relevant diagnoses. The results for the MDS also showed a bias toward the four mental illness diagnoses represented in the MDS checkboxes. A 2007 report by the Medicare Payment Advisory Commission included a recommendation to CMS to require skilled nursing facilities to use full five-digit *ICD-9-CM* codes in the MDS and to revise data collection procedures to be able to distinguish between primary and secondary diagnoses (15).

Conclusions

Assessing the reliability of nationally representative data sources for identifying nursing facility residents who have mental disorders can help researchers and policy makers evaluate the effectiveness of the PASRR process and the appropriateness of care provided in nursing facilities for those with mental illness, including their use of psychotropic drugs. Although prior studies have produced comparative estimates of the size of the nursing home resident population with mental illnesses, none to date has compared the NNHS, MAX, and MDS data sets. This study highlighted variations in the percentages of residents with diagnosed

mental disorders in nursing homes and raises questions about the reliability of the diagnoses that may be used in the screening and review process, as well as the diagnoses being assigned in the MDS and MAX. Further analysis is needed to determine how much of the variation in the MDS and MAX diagnoses may be due to differences in the population that is covered and how much to differences in facility-level coding and reporting practices. Evaluating the reliability of the NNHS has additional benefits, because the federal government relies heavily on the NNHS to estimate spending for mental health services (16,17).

Acknowledgments and disclosures

This article was prepared for the Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services under contract 280-03-1501. The authors thank Miki Satake, M.A., and Deo Bencio, B.S., who provided programming support for data analyses. Judith L. Teich, M.S.W., served as the government project officer, and Jeffrey A. Buck, Ph.D., served as adviser.

The authors report no competing interests.

References

1. Institute of Medicine: Improving the Quality of Care in Nursing Homes. Washington, DC, National Academies Press, 1986
2. Freiman MP, Arons BS, Goldman HH, et al: Nursing home reform and the mentally ill. *Health Affairs* 9(4):47–60, 1990
3. Linkins K, Robinson G, Karp J, et al: Screening for Mental Illness in Nursing Facility Applicants: Understanding Federal Requirements. SAMHSA pub no (SMA) 01-3543. Rockville, Md, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, July 2001
4. Linkins K, Lucca A, Housman M, et al: PASRR Screening for Mental Illness in Nursing Facility Applicants and Residents. DHHS pub no (SMA) 05-4039. Rockville, Md, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, 2006
5. US Department of Health and Human Services, Health Care Financing Administration: Proposed Rule: Medicare and Medicaid Programs: Preadmission Screening and Annual Resident Review. *Federal Register* 23:10851–10881, 1990
6. Office of Inspector General: Younger Nursing Facility Residents With Mental Illness: An Unidentified Population. Washington, DC, US Department of Health and Human Services, Jan 2001
7. Mechanic D, McAlpine DD: Use of nursing homes in the care of persons with severe mental illness: 1985 to 1995. *Psychiatric Services* 51:354–358, 2000
8. Shea DG, Russo PA, Smyer MA: Use of mental health services by persons with a mental illness in nursing facilities. *Journal of Aging and Health* 12:560–578, 2000
9. Jones A: The National Nursing Home Survey: 1999 Summary. *Vital and Health Statistics, Series 13, No 152*. Hyattsville, Md, National Center for Health Statistics, 2002
10. Walkup JT, Boyer CA, Kellermann SL: Reliability of Medicaid claims files for use in psychiatric diagnoses and service delivery. *Administration and Policy in Mental Health and Mental Health Services Research* 27:129–139, 2000
11. Knapp PK, Hurlburt MS, Kostello EC, et al: Child sociodemographic characteristics and common psychiatric diagnoses in Medicaid encounter data: are they valid? *Journal of Behavioral Health Services and Research* 33:444–452, 2006
12. Morris JN, Fries BE, Mehr DR, et al: MDS Cognitive Performance Scale. *Journal of Gerontology: Medical Sciences* 49:M174–M182, 1994
13. Hawes C, Morris JN, Phillips CD, et al: Reliability estimates for the Minimum Data Set for nursing home resident assessment and care screening (MDS). *Gerontologist* 35:172–178, 1995
14. Fries BE, Simon SE, Morris JN, et al: Pain in US nursing homes: validating a pain scale for the Minimum Data Set. *Gerontologist* 41:173–179, 2001
15. Report to the Congress: Promoting Greater Efficiency in Medicare. Washington, DC, Medicare Payment Advisory Commission, June 2007
16. Mark TL, Coffey RM, McKusick D, et al: National Expenditures for Mental Health Services and Substance Abuse Treatment 1991–2001. Rockville, Md, US Department of Health and Human Services, 2005
17. Mark TL, Coffey RM, Vandivort-Warren R, et al: US spending for mental health and substance abuse treatment, 1991–2001. *Health Affairs Web Exclusive*, Mar 29, 2005