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Older Adults' Reports of Formal Care Hours and Administrative Records

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Purpose: Personal assistance care is a Medicaid benefit in New York, but few data are available on its prevalence and contribution to home care. We examined these issues in a New York City sample by assessing older adults' reports of weekly home care hours and Medicaid billing records. ***Design and Methods:*** With help from New York City's Human Resources Administration, we identified all respondents in an ongoing population-based survey of Medicare enrollees who were receiving Medicaid-reimbursed personal assistance care in 1996. ***Results:*** Of respondents in the sample, 10.3% (185 of 1,902 alive through 1996) had Medicaid claims for personal assistance care. The mean was 46.1 hr/week for reported hours and 40.1 hr/week for administrative claims. Accuracy of reported hours was evident in a high correlation ($r = .91$; $p < .001$) between respondent reports and authorized claims, and a consistently high and mostly constant ratio of billed to reported hours across all categories of activities of daily living disability. ***Implications***: In this urban, low income, and mostly minority sample, older adults' reports of weekly formal care hours were valid when matched against administrative records. Respondent reports of formal care hours were valid even in complex care situations.

Key Words: Home care, Long-term care, Concordance, Administrative records, Epidemiology

Home care, especially long-term personal assistance care, is an important issue for states and the nation as the elderly population continues to grow (Halamandaris, 2001). There are two types of formal, or paid, home care: short-term home health care, particularly posthospitalization care, which stresses rehabilitation; and personal assistance care, which stresses long-term custodial care. Short-term home health care is primarily funded by Medicare. Long-term home care, or personal assistance care, is primarily funded by Medicaid or is paid out of pocket. Whereas the aim of home health care is improvement in health status, personal assistance care seeks to maintain disabled elders in their homes (Morris, Caro, & Hansan, 1998).

Home care was the fastest growing health services modality in the 1990s (Mullner, Jewell, & Mease, 1999). Spending for Medicare home health services increased almost tenfold, and spending for Medicaid personal care services quadrupled between 1987 and 1995 (Kenny, Rajan, & Soscia, 1998). Out-of-pocket spending for home care has likely increased, but consumer spending for independent home care providers is not captured in national health expenditure data (National Association for Home Care, 1999). Self-reports of home care use may be the only way to discover the amount and extent of home care services paid through out-of-pocket funds.

National surveys of health services use rely on self-reports and vary in their definitions and measures of home care use. Spector, Fleishman, Pezzin, and Spillman (2000) used data from the 1994 National Health Interview Survey and the 1994 National Long-Term Care Survey to determine that 11.8% of community-dwelling elders received formal home care. Two years later, the 1996 Medical Expenditure Panel Survey estimated the percentage of home health care use among the elderly population as 13.8% (Krauss, Machlin, & Kass, 1999). These national studies utilized administrative records and self-reports to document the use of home care services. However, they did not determine whether self-reports were consistent with billing records.

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The national studies also varied in how home care use was measured. The unit most often reported is number of visits. Visit data may be collected by category of provider, that is, skilled nursing, allied health, or homemaker–home health aide services; these visit data are usually reported in the aggregate. For home care consumers, however, the most meaningful measure of home care use is not the number of visits but the amount of time the home care provider spends in the recipient's home, that is, the number of hours received.

Hours of personal assistance care received by community-dwelling elders were reported in three recent studies. Using data from the 1994 National Long-Term Care Survey, Liu, Manton, and Aragon (2000) reported that disabled elders received an average of 12.6 hr per week of paid home care. A higher figure of 17.9 hr per week was estimated by LaPlante, Harrington, and Kang (2002), who used data from the 1994 National Health Interview Survey. More recently, data from the Asset and Health Dynamics (AHEAD) study suggest an increase in weekly hours to a mean of 34 in 1995, but the median value in this sample was 12, which is much lower (Langa, Chernow, Kabeto, & Katz, 2001).

Although prior research has compared self-reports of some aspects of health service use with administrative or provider records, we have been unable to identify studies that compare home care users' self-reports with these records. In the Medicare Alzheimer's Disease Demonstration, caregiver reports of service use were compared with administrative records, but apparently only to verify type of service, not reported volume of service use (Newcomer, Spitalny, Fox, & Yordi, 1999, p. 653). A direct comparison of reported services and administrative records in other health service domains has shown, on the whole, high levels of agreement. For example, self-reports of hospitalization were congruent with utilization records in three studies (Reijneveld & Stronks, 2001; Ritter et al., 2001; Roberts, Bergstralh, Schmidt, & Jacobsen, 1996); however, underreporting of hospitalization was reported in a study of older adults (Wallihan, Stump, & Callahan, 1999). Studies that compared self-reports of physician visits with provider records in the past year also found significant underreporting (Wallihan et al., 1999). Underreporting was evident when the time interval for self-reports was 6 months (Ritter et al., 2001), but shortening the reporting interval to 2 weeks resulted in 91% congruence between self-reports and electronic medical records (Roberts et al., 1996).

Medicaid Personal Assistance Care in New York City

Whereas home health care is a required benefit under Medicaid (and also a benefit under Part A of Medicare), personal assistance care service is an optional Medicaid-only benefit that has been adopted by only 26 states (LeBlanc, Tonner, & Harrington, 2001). States that select an optional Medicaid benefit are allowed to apply certain limitations to implementation of this benefit. There are 15 states that have limits on hours of personal care service, and 10 states have cost caps (Lince & Simone, 2002). Notably, New York is the only state that has not placed limitations on the personal care services benefit (NYSCRR, Title 18, 505.14).

Access to personal care services for low-income frail elderly persons and people with disabilities is determined by the local county social service district, which in New York City (NYC) is the Human Resources Administration's Home Care Services Program. The NYC Home Care Services Program authorizes home attendant vendors to provide personal assistance hours, which range from 4 hr of care several times each week to 24 hr of care daily. Hours of personal assistance care are assigned according to professional assessments of functional limitations. Each client has a caseworker responsible for ongoing oversight of the case, including service reauthorization at appropriate intervals. The number of patients per caseworker averages 160. The typical duration of care is several years, with some clients having been in the system for 15–20 years.

The NYC program is large. The program has been in place since the late 1980s and currently serves approximately 55,000 clients daily. The Home Care Services Program contracts with approximately 89 providers of personal care services, each with an agreed-on Medicaid case load in a specific borough ranging from 200 to 1,400 cases. Each provider employs a cadre of home attendants and must also arrange for supervisory visits by a registered nurse to the client's home at least every 90 days, at which time the home attendant's performance is reviewed and the client's functional status evaluated. In the year 2000, New York State spent $2 billion on this component of care, of which $1.6 billion was spent in NYC (Office of Management of Budget, Office of the Mayor, personal communication, December 2001). The NYC program represents 60% of the national Medicaid expenditure for this optional benefit.

In this research, we examined congruence between older adults' reports of home care hours received per week and actual Medicaid billing records. This extends our understanding of home care in three ways. First, as stated earlier, we have not been able to identify studies that provide a head-to-head comparison of reported and billed hours in home care. Second, because we obtained reports of functional status from elders in the program, we are able to investigate the relationship between functional status and both reported and billed hours. Finally, unlike other Medicaid-waiver programs, the NYC program does not impose artificial barriers to service use through limitations on hours. Thus, if the goal is to understand how home care programs meet the needs

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of older adults, results from this program may be considered *more* generalizable than results based on systems that restrict eligibility or cap hours of service.

Methods

Sample

Research Cohort.—In this research, we merged self-report data collected in an ongoing population-based survey of Medicare enrollees with administrative claims data for the same time period.

The Washington Heights–Inwood Columbia Aging Project (WHICAP) is a longitudinal population-based cohort, in which clinical and epidemiological data are collected every 1–2 years and vital status is continually updated. The cohort was first seen in 1992–1994. It was assembled through a stratified random sample drawn from Medicare enrollment files (n = 2,126) in northern Manhattan, NYC. Sampling strata for this survey included age (65–74 and 75+) and race or ethnicity (Hispanic, non-Hispanic Black, and non-Hispanic White). Thirty-seven systematic replicate subsamples were drawn with random starts, such that each subsample contained age and race–ethnicity groups of equal size. The response rate for the entire sample was 62% at baseline and 78–83% at follow-up. A comparison of participants and nonparticipants at baseline did not reveal major differences in sociodemographic characteristics. Loss to follow-up, apart from death, was mainly due to relocation and was not related to sociodemographic or clinical indicators (Tang et al., 1999).

In prior research, we merged WHICAP clinical and epidemiologic data with a variety of claims data, including hospital electronic medical records (Albert et al., 1999), and Medicare and Medicaid files (Albert, Glied, Andrews, Stern, & Mayeux, 2002). Because we begin with a known population of older adults in a defined community, whose medical status has been determined separately from administrative claims, we are able to avoid a number of biases that are characteristic of research limited to administrative claims only. Studies that rely on administrative claims alone are subject to an observation bias, in which severe cases are overrepresented (Newcomer, Clay, Luxenberg, & Miller, 1999).

Derivation of the Study Sample.—Data from the Medicaid personal assistance care program were available from 1995 through 1999. We submitted the list of WHICAP enrollees to the NYC Human Resources Administration, which administers the home care personal assistance care program. Matches were made by social security number, name, and birth date and were then inspected manually. For each individual identified in the two data systems, we retrieved all service periods of personal assistance care and the number of care hours authorized and billed for each period. We then computed the mean number of service episodes and mean number of hours across episodes for each individual by using the authorized hour indicator. The number of authorized hours better represents the time that formal care providers are in the home. Because home attendants get 1 hr off for every 8 they are in the home, they may be authorized for 8 hr and be in the home for 8 hr, but the administrative claim for billed hours will be 7 hr. Similarly, home attendants providing 24-hr care are paid only for 12 hr with an additional $17 for the overnight stay. Using "billed" hours will therefore underestimate the time in the home and exaggerate differences between reported hours and administrative claims.

We also examined Medicare home health care agency service files for 1996, obtained from the Center for Medicare and Medicaid Services (formerly the Health Care Financing Administration). We determined the proportion of respondents using Medicaid-based personal assistance care who also had episodes of Medicare home health agency care. We merged WHICAP and Medicare data in a similar fashion, matching on social security number, beneficiary claim identifier (to identify cases in which people may have made a claim through a spouse), and birth date. Medicare files for home health care agency use, however, do not record weekly hours. We used these records only to identify respondents who used the service, because these hours are not captured in Medicaid billing records.

The Columbia University–New York Presbyterian Institutional Review Board approved this research.

Measures

Self-Reported Home Care Hours.—The self-report item for home care hours in the WHICAP interview is a report of all home care hours. One question asked, "I'd like to know whether you used home care services in the past year (e.g., nurse, homemaker, home health aide or home attendant, or other auxiliary health professional)." If respondents answered yes, they were then asked, "How many hours a week do you have someone who comes to your home?" If respondents could not answer the question, a family proxy completed the interview, but proxies supplied information in only 6% of the sample.

The question has the fault of combining different kinds of service. In this regard, it is similar to the question used in the National Health Interview Survey (i.e., "during the past 12 months, did you receive care at home from a nurse or other health care professional?" See www.cdc.gov/nchs/datawh/nchsdefs/homevisits.htm). However, note that attempts to identify particular services, as attempted in the Medicare Alzheimer's Disease Demonstration, are also difficult. As Newcomer and colleagues (1999) reported, "Caregivers were sometimes

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confused about how to distinguish personal care, chore, and homemaker services from each other'' (Newcomer, Spitalny, et al., p. 665).

Accuracy of Home Care Hour Data.—Given the question format for eliciting the number of paid home care hours from respondents, measurement error is a concern. The most likely source of error is inclusion of other home care hours: either unpaid, informal care, or additional care paid for by families. We cannot distinguish between the two directly, but the administrative data allow us to identify some systematic features of respondent reports. We examined the relationship between reported and authorized hours across levels of activity of daily living (ADL) disability and derived the proportion of reported hours represented by authorized hours. A common proportion across all levels of disability would suggest that respondents are consistent in their reports. We repeated the analyses, eliminating respondents who had Medicare home health care claims and also respondents who had proxies report on home care hours.

Error in the administrative data is easier to rule out. The NYC Home Care Services Program requires that all contractors participate in an ''automated time and leave program.'' In this program, personal care attendants phone in on arrival at the home and on departure. This operation generates provider billing to New York State Medicaid and must accord with authorized hours. Tests have shown 95% agreement between authorized hours and ''time and leave'' generated billing.

Analyses

To assess agreement, we computed Pearson correlations between self-reported and billed service hours. We also categorized reported and billed service hours and computed kappa, a more stringent measure of agreement because it corrects for agreement by chance (Fleiss, 1981). For computing kappa, we divided the distribution of home care hours into five groupings (1–7, 8–20, 21–28, 29–79, and 80+ hr/week). These correspond to distribution quintiles in self-reports.

To assess the relationship between reported and authorized hours across levels of disability, we constructed a composite based on reports of difficulty in seven ADLs (two mobility indicators, as well as bathing, dressing, grooming, eating, and using the toilet). Within each level of ADL disability, we established the proportion of reported hours represented by authorized hours.

Results

We identified 185 WHICAP participants who were seen by research staff in 1996 and who also had personal assistance care service episodes in the same year, as recorded in NYC Human Resources Administration (HRA) data files. Because 1,902 of the original WHICAP cohort survived through 1996, the prevalence of personal assistance care program use in the WHICAP cohort for this year was 10.3% (185 of 1,902). These 185 people had 277 episodes of service in 1996, that is, defined periods of service in which needs were assessed and hours altered as needed. Of these 185 respondents, 20% ($n = 37$) also had claims in the 1996 Medicare files for home health agency care. Proxies reported hour information for 6% of respondents and were limited to the most disabled group of respondents.

The median interval between WHICAP interview and the closest reauthorization of personal assistance care service by HRA was 95 days, or approximately 3 months. Medicaid eligibility, as noted earlier, is required for participation in the program, and, indeed, 97% reported in the WHICAP interview that they were eligible for Medicaid. Among the 185 respondents, 7.5% ($n = 14$) were unable or refused to report the number of hours of home care they received, leaving a sample of 171 for some analyses.

As shown in Table 1, respondents in the northern Manhattan home care sample were mostly female (82.5%), African American or Hispanic (94.7%), and aged 80+ (59%; range, 71–99). Only 19% completed high school; 57.8% lived alone. More than half met the criteria for dementia either in 1996 or on follow-up, and approximately one quarter died between 1997 and 1999.

Home Care Hours

Among the 171 respondents with both reported and billed home care hours in 1996, respondents or proxies reported a mean of 46.1 hr/week (*SD*, 44.1), whereas the mean number of billed hours was 40.1 hr/week (*SD*, 46.7). In paired-comparison *t* tests, this difference was significant ($p < .001$). Families reported, on average, approximately 6 more hours per week than those provided by Medicaid. The same difference was evident when analyses were limited to respondents without claims in the Medicare home health agency file (mean reported, 42.9; mean HRA authorized, 37.2). As shown in Table 1, this difference was consistent across categories defined by sociodemographic and medical status indicators. Living arrangement was not significantly associated with number of weekly home care hours.

In the case of authorized hours, only age and disability status were associated with the number of home care hours received each week. For reported hours, age, disability, dementia status, and survival were all associated with receipt of formal care hours.

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Agreement Between Reported and Authorized Home Care Hours

The correlation between self-reported home care hours and authorized hours was .91 ($\kappa = .46$). Excluding respondents with Medicare home health agency claims (whose hours would not be recorded in the Medicaid personal assistance care data system), the correlation increased to .93 ($\kappa = .50$). Exclusion of proxy reports had little effect on agreement ($r = .92$; $\kappa = .44$). Although each correlation was large, kappa suggests only moderate agreement.

In every category of ADL disability, reported hours were higher than authorized hours, and the proportion of reported hours represented by billed hours was above 80% across levels of disability. This relationship is shown in Figure 1, which includes two axes; the left is home care hours, and the right is the proportion of reported hours represented by authorized hours.

The figure shows a number of important features. First, both reported and authorized hours increased with greater ADL disability. Second, within any level of disability, reported hours exceeded billed hours. Finally, authorized hours represent a high proportion of reported hours in all ADL disability categories, with no apparent pattern evident.

The correlation between ADL disability and reported hours was .41 ($p < .001$), and that between ADL disability and authorized hours was .36 ($p < .001$). Removing proxy reports raised the correlation to .50 and .44, respectively (both, $p < .001$).

Table 1. Reported and Authorized Weekly Home Care Hours

Characteristic (*n*)	Reported hr/week	Authorized hr/week
Gender		
Male (30)	44.0	39.4
Female (141)	46.6	40.2
Age		
<80 (70)	38.1	30.3
80+ (101)	51.7*	46.9*
Race–ethnicity		
White (8)	38.1	38.1
African American (58)	54.0	49.1
Hispanic (104)	42.2	34.8
Education		
Primary school only (117)	48.4	43.2
Some high school (21)	31.5	18.6
Completed high school (14)	57.2	50.9
Some college (19)	39.9	36.8
Living arrangement		
With family (72)	49.4	43.2
Alone (99)	43.7	37.8
Claim		
No Medicare home health agency claim, 1996 (136)	42.9	37.2
Medicare home health agency claim (35)	58.6	51.2
Deficit		
No bathing or indoor mobility deficit (54)	25.1	21.3
Indoor mobility deficit only (15)	30.1	29.0
Bathing deficit only (27)	42.9	32.7
Both indoor mobility and bathing deficits (74)	64.2***	57.0***
Dementia		
None (73)	32.9	28.1
Demented in 1996 or on follow-up (97)	54.8**	41.8
Mortality		
Survived through 1999 (128)	40.3	43.7
Died 1997–1999 (42)	61.0*	50.0**

Note: Table shows the Washington Heights–Inwood Columbia Aging Project sample, northern Manhattan, 1996, by sociodemographic and health indicators.

*$p < .05$, **$p < .01$, and ***$p < .001$ by independent samples *t* test or analysis of variance.

Discussion

To our knowledge, this research is the first to compare administrative data and reports from older persons on hours of paid home care. By matching HRA records with respondents in a population-based sample, we were able to determine that approximately 10% of older adults in our sample used NYC's Medicaid Home Care Services Program in 1996. One in five of these older adults also had Medicare home health care agency claims in the same period. Users of Medicaid personal assistance care reported high levels of disability (median of two ADL disabilities) and were likely to meet criteria for dementia (57%) or to die (25%) over the 3-year follow-up period.

Correspondence between reported and authorized home care hours was quite high. The correlation was .91, despite an average 3-month lag between interview and service authorization date. Yet reported weekly hours were also consistently higher, on average approximately 6 hours more, than HRA-authorized hours, lowering kappa to the level of moderate concordance. This difference was consistent across categories defined by sociodemographic and medical indicators. The same difference was obtained when we excluded respondents who had Medicare-reimbursed home health care agency claims or proxy-reported information.

These results suggest that respondents are consistent in their reports of home care hours (i.e., if there is error, it appears to be systematic). There also was no apparent pattern in the proportion of authorized to reported hours across levels of ADL disability.

This high level of agreement despite a relatively crude question format is impressive. Whereas the first survey question defined home care services as "a

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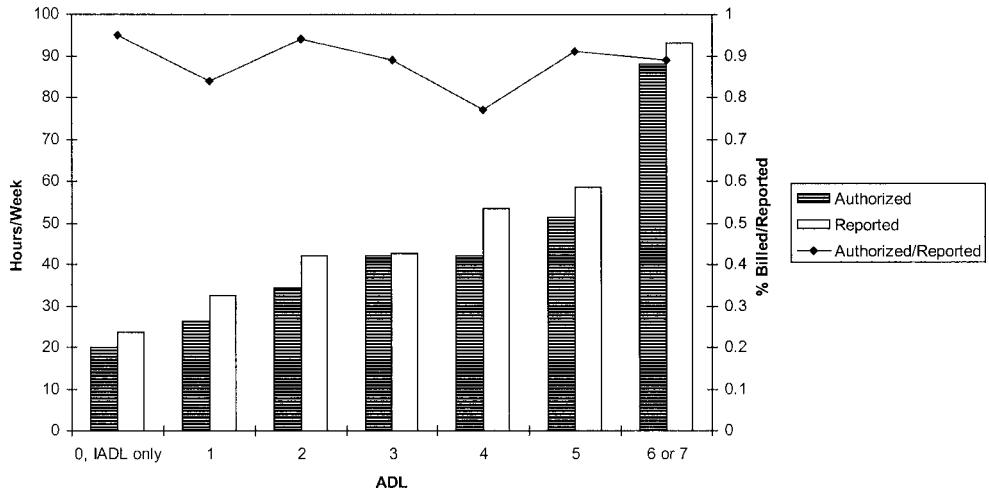

Figure 1. Home care hours by activity of daily living (ADL). IADL = instrumental ADL.

nurse, homemaker, home health aide or home attendant, or other auxiliary health professional,'' the second question was less specific: ''How many hours does someone come to your home?'' Some older adults or families may have included both formal and informal care (care provided by family, friends, or neighbors) in their estimation of weekly paid home care hours. Thus, we cannot conclude that these additional hours represent out-of-pocket expenses to families. This effort would require more careful inquiry, perhaps with a question that included a fixed list of service options and sources of payment. However, the Medicare Alzheimer's Demonstration project showed that even this strategy has limitations (Newcomer, Spitalny, et al., 1999).

The relatively small number of additional hours reported by respondents could be informal care hours provided by family or friends, though in this case one would expect the disparity between reported and authorized hours to increase with more severe levels of disability. Another possibility is that paid home attendants may have spent more hours in clients' homes than the number authorized. Interviews with home attendants in a separate project suggest that home attendants are often quite attached to clients. Home attendants in some cases find client homes satisfying places to spend time outside of working hours. Clients' homes are sometimes safe spaces for private telephone calls, storage of valuables, and so on. The two-way nature of home attendant–client exchanges requires study in its own right.

This study did not and could not examine the number of Medicare-funded home care hours provided to this sample of frail elders. In these complex and demanding care situations, attention should be given to coordination of Medicare and Medicaid home care services.

We conclude that respondent reports in this urban, low-income sample are a valid indicator of formal care. This is evident in the high correlation between reported and authorized weekly formal care hours and in the high proportion of authorized hours relative to reported hours across all categories of ADL disability. These results suggest that respondent reports of home care are valid even in complex care situations.

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