Home health and informal care utilization and costs over time in Alzheimer's disease

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Abstract

Objectives—To (1) compare home health and informal (unpaid) services utilization among patients with Alzheimer's disease (AD), (2) examine longitudinal changes in services use, and (3) estimate possible interdependence of home health and informal care utilization.

Methods—The sample is drawn from the Predictors Study, a large, multi-center cohort of patients with probable AD, prospectively followed annually for up to 7 years in three university-based AD centers. Bivariate probit models estimated the effects of patient characteristics on home health and informal care utilization.

Results—A large majority of the patients (80.6%) received informal care with a smaller proportion (18.6%) receiving home health services. Home health services utilization increased from 9.9% at baseline to 34.5% in year 4. Among users, number of days that services were provided in three-month recall increased from 21.9 to 56 days over time. Home health services utilization was significantly associated with function, depressive symptoms, being female, and not living with a spouse. Informal care utilization was significantly associated with cognition, function, comorbidities, and living with a spouse or child.

Conclusions—Home health and informal care utilization relate differently to patient characteristics. Utilization of home health care or informal care was not influenced by utilization of the other.

Keywords

dementia; cost; home health service; informal care; longitudinal study

Introduction

More than 70% of patients with Alzheimer's disease (AD) live in the community and are cared for by informal (unpaid) caregivers. A smaller proportion also receives formal (paid) services. As afflicted patients become progressively less capable of self care over time and rely on others to manage and supervise the most basic mental and physical tasks, care provision for these

patients becomes increasingly more demanding and time consuming. Increases in the number of people with AD will inevitably affect both formal and informal care provided to these patients. While many studies have examined informal and formal caregiving time in AD patients cross-sectionally, only two studies have examined longitudinally informal and formal caregiving time in AD patients.(Albert et al., 1998; Feldman et al., 2005) Both studies examined hours spent assisting with activities of daily living (ADLs) at two time-points, at baseline and at the end of one year, and reported that informal caregivers spent approximately an hour more a day assisting the patients with activities of daily living (ADLs).

An important question in care provision for AD patients is the relationship between formal and informal care. If formal and informal care are substitutes for one another, then policies that lead to increased utilization of one type of care will result in decreased utilization of the other. On the other hand, if formal and informal care are complements, then policies that lead to increased utilization in one type of care will increase utilization of the other type of service. The relationship between formal and informal care has been examined in a number of settings (Greene, 1983; Soldo, 1985; Bass & Noelker, 1987; Garber, 1989; Pezzin, Kemper, & Reschovsky, 1996; Langa et al., 2001; Lo Sasso & Johnson, 2002). Results suggest that when family caregivers are available, formal services are complements to informal care. However, few studies have examined this issue among dementia patients. The two longitudinal studies that examined caregiving hours among dementia patients both reported that over time, the proportion of time provided by paid caregivers increased relative to that provided by informal caregivers (Albert et al., 1998; Feldman et al., 2005).

In this study, we focus on one type of formal service often used by patients with AD: home health services. We aim to describe and compare utilization of home health and informal services among patients with AD and examine longitudinal changes in services use. Specifically, the goals of this study are: (1) what are the rates of home health and informal services utilization and the hours of care provided? (2) how do utilization rates and hours of care change over time? (3) what patient characteristics are associated with the rate of services use? and (4) how are home health and informal services use related to each other?

Methods

Sample

The sample used in this study is drawn from the Predictors 2 cohort, and consisted of 204 patients with probable AD recruited during 1998-2004 from three sites: Columbia University Medical Center, Johns Hopkins School of Medicine, and Massachusetts General Hospital. The study was approved by each local institutional review board. The inclusion and exclusion criteria are fully described elsewhere (Richards et al., 1993; Stern et al., 1993; Scarmeas et al., 2004). Briefly, subjects met DSM-III-R criteria for primary degenerative dementia of the Alzheimer type and NINDS-ADRDA criteria for probable AD. Enrollment required a modified Mini-Mental State examination (mMMS) score ≥30, equivalent to a score of approximately ≥16 on the Folstein Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975; Stern, 1987). Because subjects were followed at academic AD centers, they were well characterized with high degrees of certainty in their AD diagnosis. Recruitment of patients in the Predictors Study began in 1998. After the baseline visit, all patients were followed semi-annually, with annual assessments of resource utilization. During the period in which each subject was followed, missed visits were rare: 15.6% missing 1 visit, 2.5% missed 2 visits, and 1% missed 3 visits. Patients who did not respond at a particular visit could respond at a subsequent visit.

Because patterns of resource utilization differ substantially for patients living in the community and those living in institutional settings (Leon, Cheng & Neumann, 1998; Menzin et al.,

1999), we examined patients' living arrangements at each visit. Of the patients in the sample, 48 (23.5%) reported living in an institutional setting at some point during the study. Four patients reported changing living environments more than once during the study. We excluded from our analysis sample visits during which the patient was living in an institutional setting. We also excluded 6 patients with missing cost data from our analysis sample. Each of these 6 patients was assessed once at baseline and would have contributed 6 observations to the analysis sample. For the present study, the analysis sample consisted of 409 observations from 170 patients who lived at home.

Measures

Longitudinal Outcomes—Patients and informants first reported whether the patient received any home health care. For those who reported using home health care, patients and informants then reported (1) number of days services were provided in the past three months, (2) on the days of care provision, average hours per day that care was provided, and (3) out-of-pocket hourly cost for using the service. The product of these measures was used to estimate total out-of-pocket cost of home health services for each user during the three-month recall period. We adjusted cost values to constant 2004 dollars using the medical care component of the Consumer Price Index (Council of Economic Advisers 2003).

Patients and informants reported informal care patients received from up to three unpaid caregivers on basic and instrumental activities of daily living. Basic activities of daily living included eating, dressing, and personal care (e.g., bathing, toileting). Instrumental activities of daily living included shopping, chores, personal business, and transportation. We constructed a dichotomous variable to measure the rate of informal care utilization if the patient received any unpaid care. Among those who received informal care, patients and informants also reported hours of informal care received per day for each caregiving task in the following categories: 0, <3, 3-6, 6-9, 9-12, and >12 hours. We used the mean value of each category to estimate hours of care received. For subjects who reported more than 12 hours per day for a particular type of task, we coded the values to 12 hours to obtain a more conservative estimate of caregiving hours; this affected 17 observations (4%). We summed hours provided for each task to obtain an estimate of the total hours of care the patient received. We followed the literature and top coded total hours of care provision at 16 hours (Penrod et al., 1998); this affected only 6 (1%) observations. We used the national average hourly earning for all private industries for each year as the hourly wage rate to estimate unpaid caregiving costs (Council of Economic Advisers 2003).

Clinical and Demographic Characteristics—Disease progression was characterized by transition from milder stages of dementia to more severe stages, measured by MMSE (Folstein, Folstein & McHugh, 1975), one of the most widely used standardized cognitive screening test. Higher MMSE scores indicate better cognitive status. Reliability and validity of MMSE have been established in dementia patients with kappa coefficients ranging between 0.82 to 0.96 (McDowell 2006). Blessed Dementia Rating Scale (BDRS) Parts I and II was used to assess patients' functional capacity (kappa coefficient between 0.60 and 0.80); Blessed, Tomlinson, & Roth, 1968; McDowell 2006). This is a 17-point scale with higher scores indicating worse functional status.

We used Columbia University Scale for Psychopathology in Alzheimer's Disease (CUSPAD) to measure the presence or absence of psychotic symptoms, behavioral problems, and depressive symptoms (Devanand et al., 1992; Stern et al., 1997). Reliability and validity of each symptom category of CUSPAD have been established in dementia populations with kappa coefficients of 0.61-0.73 (Devanand et al., 1992). Following previous work (Devanand et al., 1992; Scarmeas et al., 2002; Holtzer et al., 2003; Scarmeas et al., 2005), the presence of

psychotic symptoms was defined by delusions, hallucinations, or illusions. The presence of behavioral problems was defined by any of the following five symptoms: wandering away from home or caregiver, verbal outbursts, physical threats or violence, agitation or restlessness, or sundowning (more confusion at night or evening, compared to during the day). The presence of depressive symptoms was defined by depressed mood (i.e., sad, depressed, blue, down in the dumps) and either difficulty sleeping or change in appetite.

We used a modified Unified Parkinson's Disease Rating Scale (UPDRS) to measure the presence or absence of extrapyramidal signs (EPS) (Stern & Hurting 1978; Richards et al., 1991; Stern et al., 1997). The UPDRS has good inter-rater reliability properties in dementia populations (Stern & Hurting 1978; Richards et al., 1991). Following our previous work (Scarmeas et al., 2004; Scarmeas et al., 2005), we constructed a dichotomous indicator for the presence of EPS if any of the following 11 items was rated 2 or higher (with 0 being normal and 4 indicating maximum impairment): speech, facial expression, tremor at rest, neck rigidity, right arm rigidity, left arm rigidity, right leg rigidity, left leg rigidity, posture, gait, or bradykinesia.

Patients' medical histories were used to construct a modified version of the Charlson index of comorbidity (Charlson et al., 1987; Scarmeas et al., 2005; Scarmeas et al., 2005). Comorbidities included items for myocardial infarction, congestive heart failure, peripheral vascular disease, hypertension, chronic obstructive pulmonary disease, arthritis, gastrointestinal diseases, liver disease, diabetes, chronic renal disease, and systemic malignancy from the baseline visit. All items received weights of one, with the exception of chronic renal disease and systemic malignancy, which were weighted two. No patients with clinical strokes, metastatic tumors, or AIDS were included in the sample. All clinical characteristics were measured at each visit. Patients' age, ethnicity, sex, highest level of education, and study site were recorded at the baseline visit; marital status and living arrangement was recorded at each visit.

Analysis

We first compared baseline socio-demographic and clinical characteristics for users and non-users of home health services and informal care. Then we examined trends over time of utilization and hours of care for home health and informal services, and estimated costs for home health and informal care utilization. We also examined trends over time in hours of care received by patients who used only informal care and those who used both types of care (Five patients who reported using only home health services were included in the home health users group). Group comparisons of categorical variables (e.g., utilization) were performed using χ^2 tests, and comparisons of continuous variables (e.g., hours) were performed using non-parametric Wilcoxon ranksum tests.

We used a bivariate probit model to estimate the effects of patient characteristics on utilization of home health services and informal care. The simultaneous modeling of the two outcomes in the bivariate probit model allows estimation of possible interdependence of utilization of home health and informal care. Such an interdependence is likely because home health services and informal care are closely related and depend on similar factors. This possible interdependence is estimated by the correlation coefficient in the bivariate probit model. A correlation coefficient that is not statistically significantly different from zero indicates that home health care and informal care are exogenous to each other and utilization of one type of care is not influenced by utilization of another. In this case, the two models can be estimated separately. On the other hand, a statistically significant correlation coefficient suggests that the two equations are an endogenous process. A positive correlation coefficient indicates that home health care and informal care are complements (e.g., increases in the utilization of informal care will increase the likelihood of using home health services) while a negative correlation

coefficient indicates that home health care and informal care are substitutes (e.g., increases in the utilization of informal care will decrease the likelihood of using home health services).

As in all binary choice models, the coefficient estimates cannot be directly interpreted as the marginal effects of the independent variables on the probabilities of receiving home health care and informal care. However, the signs of the coefficients in the probit models are consistent with the signs of the marginal probabilities. For example, a positive (negative) coefficient in the independent variable x in the home health care equation indicates that an increase in x will increase (decrease) the probability of receiving home health care. We included the same set of independent variables in both equations. All variables except age and sex were measured at each visit and were entered as time variant independent variables.

Results

Baseline Sample Characteristics

Baseline socio-demographic and clinical characteristics of the subjects are presented in Table 1. The average patient was 75 years old. Slightly over half were women (55.3%). The patients in the sample were largely non-Hispanic white (95.3%), well educated (with an average of 14.5 years of schooling), and either married (68.2%) or widowed (24.7%). Of the unmarried patients, 54.3% lived alone, 34.8% lived with a child, and 10.9% lived with other family members. At baseline, mean MMSE was 22.1 (s.d.=3.8) and mean BDRS was 3.4 (s.d.=2.2). Behavioral problems (47.4%) and EPS (46.3%) were common by CUSPAD ratings. About a third of the patients (31.2%) exhibited psychotic symptoms and a fifth (19.4%) had depressive symptoms. On average, patients had fewer than one comorbid condition at baseline (mean=0.7, s.d.=0.9); half of the patients did not have any comorbid conditions. Of the patients who reported comorbid conditions, 69.8% had hypertension, 17.4% had diabetes, 11.6% had myocardial infarction, and 10.6% had COPD.

Compared with patients who did not use any home health services, users were older (mean age=80.4 vs. 74.0) and less likely to be married (48.1% vs. 72.0%). They also reported worse functional status (mean BDRS=5.6 vs. 3.0) and more likely to have EPS (72.0% vs. 41.7%) and psychotic symptoms (55.6% vs. 25.6%). There were no differences in demographic characteristics between those who received informal care and those who did not. However, compared with patients who did not receive any informal care, those who received care reported worse cognitive (mean MMSE=21.7 vs. 23.5) and functional status (mean BDRS=3.8 vs. 2.3) as well as more comorbidities (0.8 vs. 0.4).

Utilization and Costs of Home Health and Informal Care

Figure 1 shows utilization and costs of care for home health services and informal care over 4 years. On average, 18.6% of the patients in the sample reported receiving home health services during the past three months, and among patients who received home health care, care was provided on an average of 33.1 days during the past three months. However, intensity of use varied tremendously: During the three-month recall period, the lowest quartile of patients who used home health services reported using five days or fewer of care, while the highest quartile of patients used more than 60 days of care. On the days when services were provided, patients received an average of 9.3 hours per day. Over time, the percentage of patients who reported using home health services increased steadily from 9.9% at baseline to 34.5% in year 4. Among those who used home health services, the number of days that services were provided also increased steadily from 21.9 to 56 days in the past 3 months, but hours per day on days care was provided remained relatively stable over time.

Among patients who received home health services, the large majority of care was paid for out-of-pocket (87.1%); a small proportion was paid for by Medicare (5.9%) or by other insurances (8.2%). All but one patient reported a single payment source. Among those who paid for home health services out-of-pocket, annual cost increased from $12,033 to $21,148 over 4 years. Because utilization rate of home health services and number of days of services were provided both increased, annual cost per patient for the entire sample also increased from $1,190 at baseline to $7,292 in year 4.

Compared with utilization of home health services, the majority of patients (80.6%) received some informal care, increasing from 76.5% at baseline to 88.0% in year 4. Among those who received informal care, caregiving hours increased from 4.0 hours per day at baseline to 7.6 hours in year 4, with estimated cost rising from $20,590 at baseline to $43,031 in year 4.

Utilization of Home Health Services in Relation to Informal Care Utilization

Figure 2 compares home health and informal caregiving hours patients received over time for those who used informal care only and those who used both types of care. As noted before, five patients who reported using home health services only were included in the home health users group. For all years, patients who received both home health and informal care and those who received informal care only received similar amount of informal care. Both home health and informal care hours increased over time: For patients who received informal care only, care hours increased from 3.5 hours per day (24.4 hours per week) at baseline to 5.6 hours per day (39.5 hours per week) in year 4. For patients who received both types of services, informal care hours increased from 3.3 hours per day (23.4 hours per week) at baseline to 5.9 hours per day (41.5 hours per week) in year 4, and home health services hours increased from 0.3 hours per day (2.4 hours per week) at baseline to 3.6 hours per day (25.1 hours per week) in year 4. Among patients who used both types of services, because of faster increases in home health care hours, the ratio of informal to home health care hours decreased over time from 9.8 at baseline to 1.7 in year 4 (mean=4.6).

Multivariate Results

Table 2 presents bivariate probit regression results on utilization of home health services and informal care. Controlling for other clinical characteristics, patients with worse cognition and functioning were more likely to receive both home health and informal care, although the effects of cognition on home health utilization was only marginally significant. Utilization of home health services was also significantly associated with depressive symptoms, being female, and not living with a spouse. Utilization of informal care was significantly associated with more comorbid conditions, and living either with a spouse or a child. Patients with psychotic symptoms were more likely to receive home health services but less likely to receive informal care; however, the associations were only marginally significant. Finally, the correlation coefficient between the two equations (-0.129) was statistically insignificant, suggesting that, in this sample, utilization of home health care or informal care was not influenced by utilization of the other.

Discussion

In this study, we estimated empirically the long-term trajectories of informal care and home health services utilization and costs for a sample of community-living patients initially at early stages of AD and examined their utilization in relation to each other and to patients' clinical and socio-demographic characteristics. Consistent with many studies that examined informal caregiving, we confirmed the high utilization rate and costs of caring for patients with AD (Harrow et al., 2004). We estimated that, on average, 80% of AD patients living at home received some informal care. Those receiving care received approximately 33.1 hours of care

per week, at an estimated cost of $25,381 per patient per year. Both rates of informal care utilization and caregiving hours (and costs) increased substantially at each subsequent follow-up, with costs rising from $20,590 per patient per year at baseline (4.0 hours per day), when all patients were at the early stages of the disease, to $43,030 per patient per year in year 4 (7.6 hours per day). These results are consistent with two studies that reported an average increase of an hour per day in informal caregiving time over a year (Albert et al., 1998; Feldman et al., 2005).

Compared to informal care, rate of home health services utilization among patients with AD was relatively low. On average, fewer than 20% of the patients in the sample reported receiving home health services during the three-month assessment period. Over time, however, utilization of rate of home health services increased more than three-fold, from less than 10% at baseline to over 30% in year 4. In addition to utilization rate, number of days that home health services were provided also increased steadily over time. Consistent with existing reports in the literature, the faster rate of increase in home health services utilization as compared to informal care provision resulted in decreases in the ratio of informal to home health care hours over time from 9.8 at baseline to 1.7 in year 4 (Albert et al., 1998; Wimo, von Strauss, Nordberg, Sassi, & Johansson, 2002).

Because utilization rate and days of service provided both increased over time, the cost impact of home health services utilization is important at a per capita level as well as a per user level. At a per capita level, per patient cost of home health services was low when patients were at early stages of the disease but became an increasingly important component of cost over time. At a per user level, the cost of home health services use was substantial, almost doubling from $12,033 to $21,148 during the 4-year study period.

It should be noted that while we included all home health services (e.g., provided by home health agency providers and privately hired individuals supervised by the family), only out-of-pocket costs were reported. Although the large majority of home health services were paid for out-of-pocket, 13% of the patients reported Medicare and other insurance as payment sources. Because payments by Medicare or other insurance were not included in this study, our results are a conservative estimate of the true total costs of home health services.

Studies on the relationship between formal and informal care on samples of non-demented elderly have reported inconsistent results on whether they are substitutes or complements. How formal and informal care are related for patients with dementia is not yet clear. The few studies that examined this issue among dementia patients reported no substitution effect between formal and informal services use (Albert et al., 1998). Results from this study suggest utilization of home health or informal care was not influence by utilization of the other. However, because the number of patients who used home health services was relatively small, we did not examine the relationship between hours of home health or informal care used. Our multivariate analyses also suggest that home health and informal care utilization relate differently to patients' clinical characteristics: Higher utilization of home health services was significantly associated with function, depressive symptoms, being female, and not living with a spouse; Higher utilization of informal care was significantly associated with cognition, function, comorbidities, and living either with a spouse or a child.

Amount of care patients receive depends not only on patients' clinical characteristics, but also on many other socio-demographic factors, including availability of informal caregivers and access to and affordability of formal care. When informal caregivers are available, patients are likely to receive informal care. However, when asked to report the amount of time spent on providing care to their loved ones, many informal caregivers (22%) may be unable to distinguish time spend with a dementia patients and actual "help" hours (Albert et al., 1998).

For patients at milder stages of dementia as in our study, the proportion of caregivers who are unable to report actual caregiving hours are likely to be higher. As dementia worsens, caregivers may be more aware of their caregiving role and more likely to identify hours spent with the patient as providing care. This may partially explain why between year 2 and 3, while utilization rate of informal care remained steady, informal caregiving hours (hence imputed costs) increased dramatically.

As afflicted patients become progressively less able of self care over time and rely on others to manage and supervise basic mental and physical tasks, family members and friends may be compelled to increase informal caregivng hours. However, caregiver time constraints, stress and burnout, and increasingly more demanding caregiving tasks because of patients' worsening disease severity may also lead family members to increasingly rely on formal services. Indeed, one study reported that formal caregivers were less likely to provide care during the night and early morning but more likely to take patients for doctor visits during the day (Albert et al., 1998). This may reflect use of formal services during informal caregivers' work hours and specialization of care provision between formal and informal caregivers.

National and state policies increasingly recognize the public sector's role in sustaining informal, family caregiving. The National Family Caregiver Support Program (NFSCP), modeled on previous state endeavors and operating since 2000, has distributed over 125 million annually to the states to provide a range of services to caregivers. These services include providing information about and assistance to access support services, counseling, training and respite care. States also have a variety of programs to support family caregivers. Most use Medicaid funds to support home and community-based care; Some also have designed their own state-funded programs to complement NFSCP or Medicaid programs. A tax credit for family caregivers, allowing individuals a deduction for qualified long-term care insurance premiums, remains under consideration (as the Long-Term Care and Retirement Security Act of 2005).

This study has several limitations. First, patients in this sample were selected from tertiary care university hospitals and specialized diagnostic and treatment centers and thus represent a nonrandom sample of those affected by AD in the population. Patients in our sample also were predominantly white and highly educated. Although not asked in the study, the high education levels of the patients suggest that they are unlikely to be eligible to receive publicly paid home healthcare services (e.g., Medicaid). Also, all patients were at early stages of dementia at baseline, and had few comorbid conditions. The relationship between utilization of paid home healthcare and informal care may be different among patients with lower income levels and those with moderate or severe dementia. In addition, characteristics of the patients' family structure, e.g., number and gender of children, availability of other female family members, may affect informal caregiving hours patients receive. Our models are therefore limited to having controlled for the only variable in the study that reflect the patients' family structure: the patients' living arrangement. The relative homogeneity of ethnicity distribution in this sample also suggests that caution is needed in generalizing the results of this study to patients of other ethnicities and to community AD patients.

Second, in this study we only focused on one type of formal care, home health services utilization. Patients with AD may use other types of formal services such as adult daycare, respite care, or other services, which may influence the utilization of home health services or informal care. Utilization rate of adult daycare and overnight respite care were reported in the Predictors study, however, utilization rate of these services were low (adult daycare, 7.6%, n=13; respite care, 2.3%, n=4) and unlikely to have substantial influence on home health services or informal care. As a secondary analysis, we examined utilization rates of these two types of care over time and found that, unlike the increases in home health services utilization, utilization rates of these services did not increase over time. Earlier studies have reported that

dementia caregivers consistently under-use available formal care resources (Gwyther, 1989) and have attributed low utilization rates to poor knowledge of availability of such resources (Vetter et al., 1998). Because of the longitudinal study design of the Predictors Study, future studies will examine changes in formal services utilization over longer periods of time.

It should be noted that service utilization data we used in this study are self-reported and therefore are subject to difficulties of recall; they were not verified against provider or Medicare data. There are two relevant issues. One, patients who used services infrequently may have more difficulty recalling the amount of services used and may lead to underestimates of total services use. Second, if the difficulties of recall are not distributed randomly in the sample (e.g., sicker patients have more difficulties of recalling use of care), then our estimates may be biased. Because both patients and informants provided information for this study, and earlier studies showed that caregivers can accurately report information on care recipients' medical conditions, there is no reason to believe that difficulties of recall are not distributed randomly in the sample. Also, because neither informal care nor home health care utilization are uncommon among our sample, and whether or not services were used is almost certain to be less problematic to recall than the actual amount of use, recall biases are likely to be minimal.

In general, confidence in our findings is strengthened by several factors. A major advantage of the study lies in the careful diagnosis and clinical follow-up that patients received. Clinical diagnosis took place in University AD centers and was based on uniform application of widely accepted criteria via consensus diagnostic conference procedures. Clinical signs were ascertained and coded in a standardized fashion at each visit, and clinical diagnosis of AD has been confirmed in a high proportion (93%) of those who have come to postmortem evaluation. The study followed patients prospectively, eliminating potential biases inherent in retrospective chart reviews. The cohort also had high rates of follow-up participation with few missing data. Finally, patients were recruited at early stages of the disease and followed for long periods of time. Analysis therefore is not compressed in time and the cohort describes the full range of progression over time, making longer-term effects on costs more easily interpreted.

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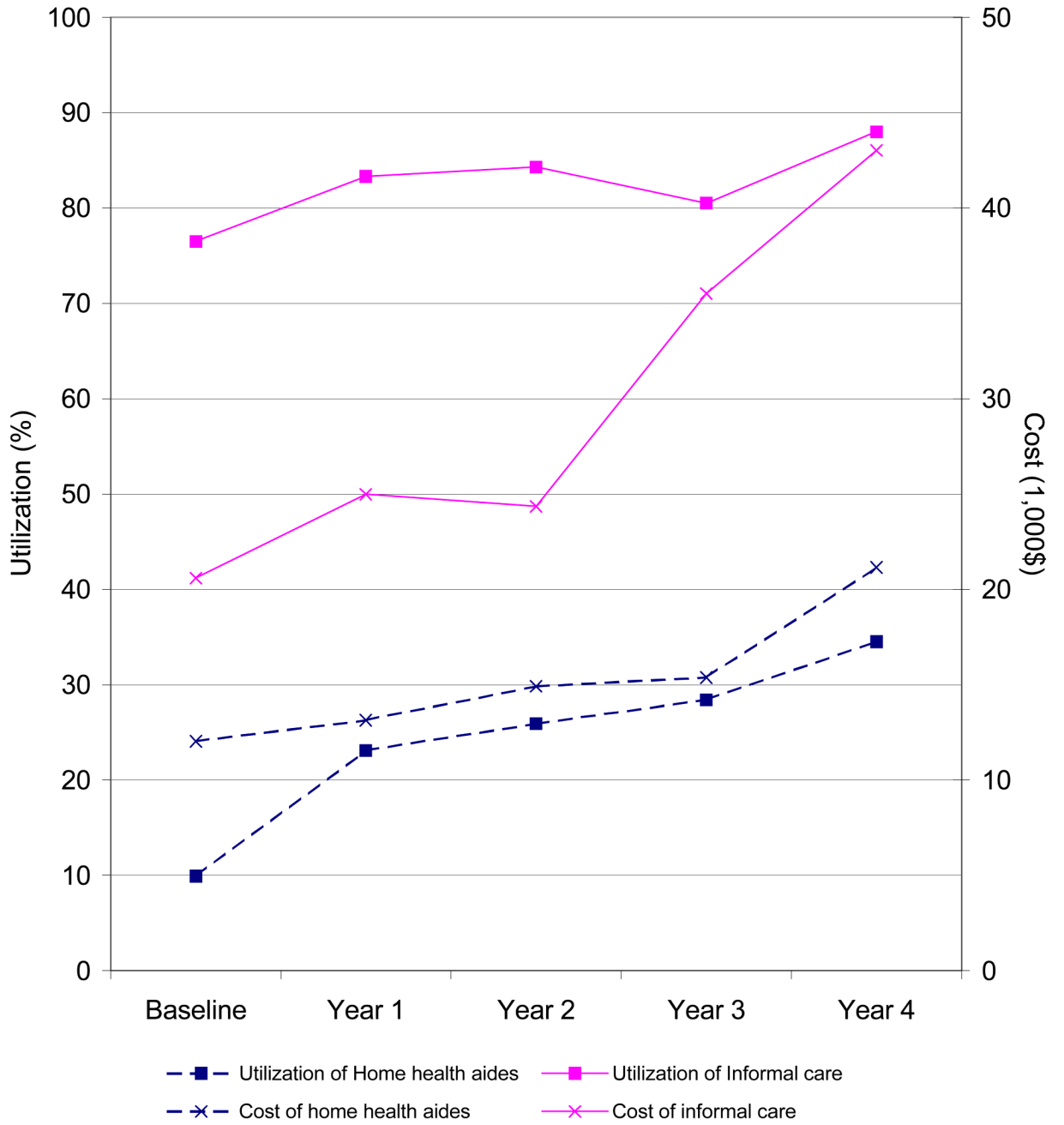
Figure 1. Utilization and cost of home health and informal care
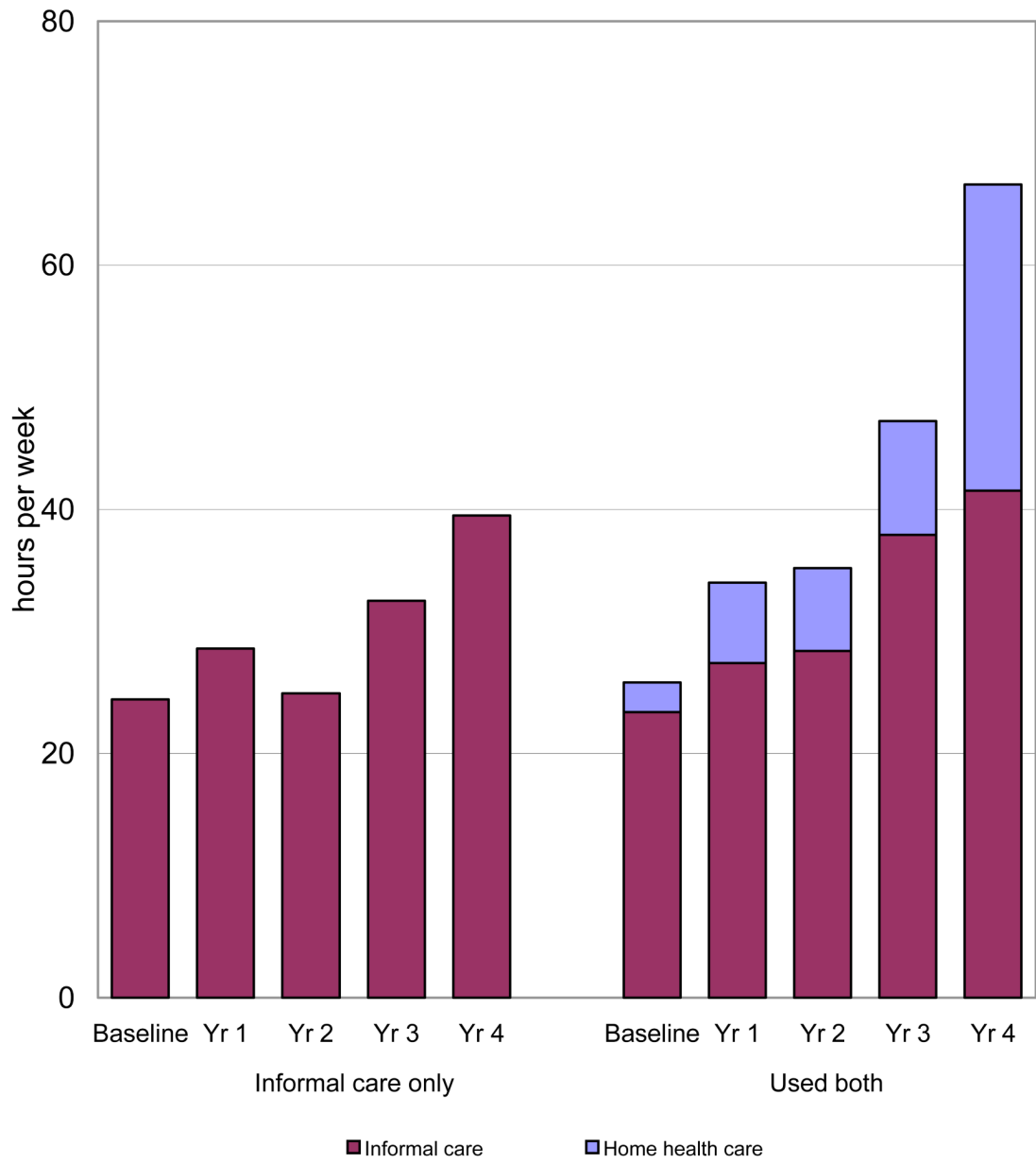
Figure 2. Home health and informal hours provided per week

Table 1

Patients' baseline characteristics, by utilization of home health and informal services utilization (n=170)

	All Sample	Home Health Services Non-user	Home Health Services User	Informal Care Non-user	Informal Care User
Sample size	170	143	27	40	130
Socio-demographic Variables					
Age at baseline, means yrs (sd)	75.0	74.0***	80.4	74.5	75.2
	(7.6)	(7.5)	(5.3)	(7.0)	(7.8)
Women (%)	55.3	53.8	63.0	52.5	56.2
Race (%)					
White	95.3	95.8	92.6	92.5	96.2
Black	4.1	3.5	7.4	5.0	3.8
Other race	0.6	0.7	0.0	2.5	0.0
Years of schooling, mean (sd)	14.5	14.6	13.9	15.2*	14.3
	(3.2)	(3.3)	(3.4)	(3.3)	(3.3)
Marital Status (%)					
Married	68.2	72.0**	48.1	72.5	66.9
Widowed	24.7	23.1	33.3	20.0	26.2
Never married	3.5	2.1	11.1	5.0	3.1
Divorced/separated	3.5	2.8	7.4	2.5	3.8
Living arrangement among unmarried patients					
Alone	54.3	54.5	54.3	54.5	44.2
With a child	34.8	36.4	34.3	18.2	32.6
With another family member	10.9	9.1	11.4	27.3	18.6
Site					
Columbia	51.8	51.0	55.6	65.0	47.7
Johns Hopkins	25.9	26.6	22.2	7.5	26.9
Massachusetts General	22.4	22.4	22.2	27.5	25.4
Clinical Characteristics					
MMSE [a], mean (sd)	22.1	22.3	21.0	23.5***	21.7
	(3.8)	(3.7)	(4.1)	(3.3)	(3.8)
BDRS total [b], mean (sd)	3.4	3.0***	5.6	2.3***	3.8
	(2.2)	(1.9)	(2.5)	(1.8)	(2.2)
Number of comorbidities	0.7	0.7	1.1	0.4**	0.8
	(0.9)	(0.8)	(1.1)	(0.6)	(0.9)
Behavioral problems (%)	47.4	39.9	55.6	32.5	45.4
EPS [c] (%)	46.3	41.7**	72.0	35.1	49.6
Depressive symptoms (%)	19.4	18.9	22.2	25.0	17.7
Psychotic symptoms (%)	31.2	26.6**	55.6	30.0	31.5

*
differences between users and non-users significant at p < .10,

**
differences between users and non-users significant at p < .05,

***
differences between users and non-users significant at p < .01.

[a] MMSE = Mini-Mental State Examination (range=0-30);

[b] BDRS = Blessed Dementia Rating Scale (range=0-17);

[c] EPS = Extrapyramidal signs

Table 2

Bivariate probit analyses of utilization of home health services and informal care (n=409)

	Home Health Services	Informal Care
Socio-demographic Variables		
Age at baseline	0.019	-0.002
	(0.018)	(0.011)
Women (1=yes, 0=no)	0.520 **	-0.051
	(0.248)	(0.195)
Living arrangements (reference=other)		
With spouse	-0.655 **	0.549 *
	(0.330)	(0.341)
With a child	-0.417	1.104 **
	(0.408)	(0.497)
Alone	-0.099	0.315
	(0.414)	(0.404)
Site (reference=Columbia)		
Johns Hopkins	-0.447	0.314
	(0.291)	(0.297)
Massachusetts General	0.059	-0.103
	(0.257)	(0.200)
Clinical Characteristics		
MMSE score [a]	-0.039 *	-0.057 **
	(0.021)	(0.024)
BDRS score [b]	0.246 ***	0.170 ***
	(0.047)	(0.052)
Number of comorbidities	0.032	0.391 ***
	(0.112)	(0.121)
Behavioral problems (1=present, 0=absent)	-0.053	-0.030
	(0.197)	(0.173)
EPS [c] (1=present, 0=absent)	-0.059	0.024
	(0.248)	(0.277)
Depressive symptoms (1=present, 0=absent)	0.468 **	-0.319
	(0.203)	(0.217)
Psychotic symptoms (1=present, 0=absent)	0.274 *	-0.365 *
	(0.170)	(0.201)
Year	0.044	-0.049
	(0.084)	(0.084)
Constant	-2.751	1.122
	(1.261)	(1.021)
Log likelihood	-273.040	
Correlation coefficient	-0.129	
	(0.148)	

Note: Standard deviations are shown in parentheses.

*
p < .10,

**
p < .05,

***
p < .01

[a] MMSE = Mini-Mental State Examination (range=0-30);

[b] BDRS = Blessed Dementia Rating Scale (range=0-17);

[c] EPS = Extrapyramidal signs