

Informal Caregivers and the Risk of Nursing Home Admission Among Individuals Enrolled in the Program of All-Inclusive Care for the Elderly

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Purpose: We sought to determine whether participants in the Program of All-Inclusive Care for the Elderly (PACE) with an informal caregiver have a higher or lower risk of nursing home admission than those without caregivers. **Design and Methods:** We performed a secondary data analysis of 3,189 participants aged 55 years or older who were enrolled in 11 PACE programs during the period from June 1, 1990 through June 30, 1998. Cox proportional hazard models determined whether having any caregiver, as well as specific caregiver characteristics, such as either living separately from the enrollee, being over the age of 75 years, providing personal care, not reducing or quitting work to provide care, or not being a spouse, predicted time to nursing home admission. **Results:** Fewer than half of the participants (49.4%) lived with a caregiver, and 12.4% had no caregiver. Individuals who lived with their caregiver were frailer than either those who lived separately or those without a caregiver. We measured frailty in terms of functional and cognitive status, incontinence, and multiple behavioral disturbances. The presence of a caregiver did not change the risk for

institutionalization. None of the caregiver characteristics were associated with a higher risk of nursing home admission. **Implications:** Unlike individuals in the general population, participants in PACE who lack an informal caregiver are not at higher risk of institutionalization. Further research is required to ascertain whether PACE's comprehensive formal services compensate for the lack of informal caregiving in limiting the risk for institutionalization.

Key Words: Informal support, Institutionalization, PACE, Social support

As older adults become increasingly dependent, their care needs may be met by either informal care, that is, unpaid care provided by family and friends, or by formal care, namely, paid care. The relationships among informal care, formal care, and the subsequent risk of nursing home admission are complex. Several studies involving frail older adults—those at the highest risk of institutionalization—have shown that issues of caregiving are at least as important in predicting nursing home admission as are patient-specific risk factors (Greene & Ondrich, 1990; Liu, Coughlin, & McBride, 1991; Liu, McBride, & Coughlin, 1994; Tsuji, Whalen, & Finucane, 1995).

In certain circumstances, the presence of a caregiver has been associated with a lower risk of nursing home admission (Newman, Struyk, Wright & Rice, 1990; Hanley, Alexcih, Wiener, & Kennell, 1990). There are many possible reasons for this reduced risk. In standard care, the presence of a caregiver may either substitute for formal care, or it may facilitate access to needed formal services that in turn prevent functional deterioration and the need for nursing home care. In particular, an individual with a caregiver may be able to opt for community-based alternatives to nursing home admission (Weissert & Hedrick, 1994). In

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addition, caregiving may provide emotional and other support that may slow decline as a result of social interaction (Temkin-Greener et al., 2004).

However, the studies by Newman and colleagues (1990) and by Hanley and associates (1990) showed that, in many circumstances, the presence of a caregiver actually leads to an increase in risk of institutionalization. A review article by Miller and Weissert (2000) showed that, of 16 studies that evaluated the role of an informal caregiver in predicting nursing home admission, 9 showed an increase in risk, 1 showed a decrease in risk, and 6 showed no significant association. Although these results might initially be surprising, further evaluation of the caregiving situation provides insights into why these results may occur. Caregiver stress and caregiver "burnout" have been associated with an increased risk of institutionalization (Colerick & George, 1986; Jette, Tennstedt, & Crawford, 1995; McFall & Miller, 1992; Tsuji et al., 1995; Zarit, Reever, & Bach-Peterson, 1980). Several categories of "high-risk" caregivers, that is, those who are more likely to admit the patient to a nursing home, have been identified. These include caregivers who give personal care (Montgomery & Kosloski, 1994), those living apart from the patient (Montgomery & Kosloski; Tsuji et al.), nonspousal caregivers (McFall & Miller; McKinlay, Crawford, & Tennstedt, 1995; Montgomery & Kosloski; Paton, Graney, Elam, & Appelgate, 1993) and those working full time (Colerick & George).

The use of formal care has frequently been associated with an increased risk of nursing home admission (Hanley et al., 1990; Jette et al., 1995; McFall & Miller, 1992; Newman et al., 1990; Pruchno, Michaels, & Potashnik, 1990). Although this might initially seem counterintuitive, McFall and Miller postulate that the exposure to formal care may be "too little, too late" to forestall the need for nursing care and supervision. In other words, turning to formal, community-based services may be a marker for increased need, and for caregivers who are already significantly stressed and on the verge of burnout. Individuals with caregivers who use more community-based services might therefore be at particularly high risk of institutionalization, compared with those who use fewer services.

The Program of All-Inclusive Care for the Elderly (PACE) is a community-based system of preventive, primary, acute, and long-term care that cares for dually eligible (Medicaid and Medicare) older adults who qualify for nursing home care (Eng, Pedulla, Eleazer, McCann, & Fox, 1997). A stated goal of the program is to maintain or improve the functional independence of its participants, and thus prevent or delay institutionalization. To meet this goal, PACE provides extensive formal services, including day care, home care, and meals. Participants receive care from an interdisciplinary health care team that is based at a day health center, where they are routinely seen by nurses, social workers, physicians, and recre-

ational, occupational, and physical therapists. Recognizing the important role that informal caregivers play in patients' care, PACE, through its services, supports not only the care recipients but their caregivers as well. This is done through caregiver education, provision of formal care that reduces the burdens on informal caregivers, short respite through day center attendance, and longer respite care. A further description of the model of care and its financing have been published elsewhere (Gross, Temkin-Greener, Kunitz, & Mukamel, 2004; Temkin-Greener, Meiners, & Gruenberg, 2001).

PACE, which offers extensive but controlled access to formal services, provides an important opportunity to evaluate the effects of the presence of a caregiver in a frail group of individuals who have access to needed services. In other words, the reduction in risk of nursing home admission for individuals with caregivers in standard care may be a result of increased access to preventive care and other formal services that in turn reduce risk. The PACE model, which provides formal care based on need, rather than access, provides the opportunity to evaluate the role of the caregivers themselves, rather than the dual roles of caregiver and resulting formal services. Specifically, does the presence of a caregiver in this select group with access to substantial and presumably appropriate formal services portend a high risk of institutionalization, as suggested by McFall and Miller? In other words, is PACE a transitional program for at-risk participants with caregivers? Or does the presence of a caregiver mitigate that risk?

We hypothesized that, for PACE participants, unlike other community-dwelling older adults, having a caregiver would not be a factor influencing nursing home admission. This is because the capitated program has incentives to avoid institutionalization and thus provides an extensive array of formal care when it is needed, possibly compensating for the lack of informal support. Furthermore, if PACE were successful in supporting the caregiver, among PACE enrollees we might not observe differences in the probability of nursing home admission based on the characteristics of the caregiver. Adjusting for baseline risk factors for institutionalization, we tested these hypotheses by examining the relationship between having a caregiver, the caregiver characteristics, and nursing home admission among PACE enrollees.

Methods

Study Population

Because young PACE programs may be on a learning curve, we included only participants who were enrolled at least 2 years after the inception of each program, thus allowing the investigation of practices and experience in more mature programs. We evaluated the 4,809 participants aged 55 and older who were enrolled in 11 mature dually

capitated (Medicare and Medicaid) PACE programs between June 1, 1990 and June 30, 1998. We excluded a total of 1,073 participants who were not assessed within 30 days of enrollment as well as 65 participants who were in the program for fewer than 30 days. Of the remainder, 348 had incomplete caregiver information, leaving 3,323 participants. We also excluded the 134 participants who were enrolled from a long-term nursing home stay, because their baseline living situation with respect to a caregiver was unclear. This left a total of 3,189 participants in 11 programs for evaluation (66.3% of the original sample). Participants who were not assessed within 30 days, mostly enrolled from two sites, did not differ from the rest of the participants with respect to gender or risk of nursing home admission, but they were slightly younger, with a mean age of 77.4 versus 78.8. Results were similar when we repeated the analyses but excluded these two sites, indicating that this exclusion does not bias the results.

Source of Data

We used data from the first 11 PACE sites. Because PACE was a demonstration project during the study period, each site was required by the Centers for Medicare and Medicaid Services (then the Health Care Financing Administration) to collect a standard data set, including individual-level baseline sociodemographic, health, and functional status information, information about presence and type of caregiver, as well as regular updates on nursing home utilization. Several members of the interdisciplinary team collected the data. The social worker collected data on sociodemographics, caregivers, self-reported health, and mental status. The nurse collected data on function, behavior, and nursing home utilization. Physicians collected data on the presence of chronic conditions. The data was compiled at a central data-coordinating center.

The reliability of the data was ensured in three ways: through a training program for personnel at the sites who were responsible for entering data; by having uniquely designed data-entry software that was used at all sites; and by using a manual that gave detailed explanations of information to be entered. These requirements ensured an interrater reliability of at least 90%. These approaches, including the training program, have been described elsewhere (Mukamel, Temkin-Greener, & Clark, 1998).

Variables

Predictors of Nursing Home Admission.—We used participant-level variables that were determined at enrollment into PACE. Demographics included age, gender, and ethnicity.

Baseline activities of daily living (ADLs) were assessed through observation by a registered nurse who, as part of PACE training, received extensive

instruction on the measurement of ADLs and instrumental ADLs (IADLs) and who was evaluated for reliability through a grading of assessments of videotaped patients. According to Katz (1983), there are six basic ADLs: bathing, dressing, toileting, transferring, continence, and feeding. We tallied all measurements other than continence and reported the sum as the number of ADLs, from 0 to 5, that required either supervision or assistance; higher numbers reflected greater dependence. We treated continence as a separate risk factor because of the concern that it might independently affect caregiver stress and therefore nursing home admission risk.

IADLs were evaluated and summed in the same way, with the number requiring supervision ranging from 0 to 8. The IADLs assessed were preparing meals, shopping, doing housework, doing laundry, performing heavy chores, managing money, taking medications, and using transportation.

In the data set, bowel and bladder incontinence were recorded as absent, seldom (less than once per week), and frequent (more than once per week), with a category for catheter use for those with urinary incontinence. To minimize assessor bias, we dichotomized the measures to present or absent. We reran the regressions, dichotomizing frequent versus not, with no substantial changes in predictors.

We measured health in two ways. Self-reported health status was reported as excellent, good, fair, or poor. In addition, we tallied the number of chronic conditions from a list of 59 conditions.

Mental status was measured via the 10-point Short Portable Mental Status Questionnaire. The number of errors or unanswered responses is recorded from 0 to 10, with higher numbers representing higher levels of cognitive impairment (Pfeiffer, 1975; Welch & West, 1999).

Using the *PACE Data Collection Manual*, we dichotomized several behavioral problems, namely, wandering, verbal disruption, physical aggression, regressive behavior, and hallucinations, to present or absent (PACE/On Lok, 1993). The manual defines wandering as straying caused by impaired judgment. Verbal disruption is defined as yelling, baiting, threatening, and the like. Physical aggression is defined as being assaultive or combative to self or others with intent for injury. Regressive behavior is defined as childish, repetitive, or antisocial physical behavior that creates disruption with others. Hallucinations are defined as visual, auditory, or tactile perceptions that have no basis in reality. We also dichotomized vision, hearing, and communication difficulties (expressive, receptive, or both).

We used two programmatic variables for this study: site and program age, measured as time from Medicare and Medicaid capitation of the program (reflecting the full implementation of the PACE model) to participant enrollment. We used the latter measure to evaluate whether site maturity was related to nursing home admission.

On the basis of discussions with the individual and his or her family, the PACE social workers obtained information with respect to caregivers. A household caregiver was identified if the individual lived with someone who provided care in the home. A nonhousehold caregiver was defined as “family, friends, neighbors; anyone who provides support but does not live in the same residence.”

We divided the study population into three categories: no caregiver, nonhousehold caregiver, and household caregiver. If a participant had both a nonhousehold and a household caregiver, we included them in the household caregiver category, thereby creating mutually exclusive categories.

We defined five additional subgroups of caregivers on the basis of characteristics that make them more likely to burn out and that in turn may put their care recipient at higher risk for nursing home admission, based on previous literature. The five groups included those living separately from the patient, those over the age of 75, caregivers who had not cut down or quit work to provide care, those providing personal care, or nonspousal caregivers. We defined caregivers over the age of 75 a priori as being at high risk, because individuals over the age of 75 have frequently been categorized in the literature as “old old,” with increased vulnerability to adverse outcomes (Roose et al., 2004; Soumerai, McLaughlin, Ross-Degnan, Christiansen, & Gurwitz, 2002)

Outcome.—We defined the outcome variable as time to a long-term nursing home admission, defined as a stay of 30 days or longer. We used the 30-day criterion because many PACE programs use nursing homes on a short-term basis to provide subacute and other types of care that do not constitute long-term institutionalization. In addition, a 30-day stay has face validity, in that it constitutes a substantial duration for the patient and substantial utilization of resources for the program.

We measured time as number of days from subject enrollment to first nursing home admission. We censored participants if they died, disenrolled from the program, or were admitted to the nursing home, or when data collection ended.

Statistical Analyses

To describe the characteristics of the PACE population, we compared individual characteristics as to the three main caregiver categories: no caregiver, household caregiver, or nonhousehold caregiver. We used chi-square tests and an analysis of variance to identify statistically significant differences between the groups.

To examine the effects of having a caregiver, and the type of caregiver, on the time to nursing home admission, we estimated a Cox proportional hazard model. We entered the variable identifying whether

the individual had a caregiver, as well as dummy variables for all five caregiver subcategories, and we also adjusted for other baseline risk factors. We stratified the model by site.

If some of the explanatory variables are highly correlated, standard errors will be inflated and one might erroneously conclude that there are no significant relationships between nursing home admission and the risk factor. We calculated a variable inflation factor for each independent variable (Kleinbaum, Kupper, & Muller, 1988). None of the variables had a variable inflation factor greater than 2, indicating that collinearity is not present in this data set.

Results

Three hundred and ninety-four participants (12.4%) had no caregiver; 1,219 (38.2%) had only a nonhousehold caregiver; and 1,576 (49.4%) had a household caregiver.

Baseline differences between participants according to the main caregiver category are presented in Table 1. Of the three groups, individuals with household caregivers were the frailest by multiple measures, with the highest prevalence of bowel and urinary incontinence, hallucinations, regression, physical aggression, verbal disruption, wandering, communication impairment, cognitive impairment, and ADL and IADL impairment. These individuals were more likely than those in the other groups to be non-White, and they had the youngest overall mean age.

There were substantial site differences by caregiver category (data not presented in Table). The percentage of participants with no caregiver ranged from 1.2% to 38.5% across sites, and the percentage with a household caregiver ranged from 18.9 to 94.9%. The difference between sites was significant at the $p < .0001$ level.

Overall, there were 253 admissions to a nursing home, representing 7.9% of the sample population. The median time to admission was 323 days.

The bivariate predictors of time to nursing home admission in this population are shown in Table 2. Before we adjusted for other characteristics, we found that age, race, functional status (ADL and IADL dependency), incontinence (bowel and urinary), cognition, verbal disruption, hallucinations, communication impairment, and program maturity were predictive of nursing home admission. Presence of a caregiver did not predict time to nursing home admission in the bivariate analysis.

The independent contributions to nursing home admission risk are presented in the multivariate regression of Table 3. Overall, the presence of a caregiver did not predict time to nursing home admission. The hazard ratio for an individual with a caregiver was 0.86 (95% confidence interval = 0.49–1.50), when compared with individuals without caregivers, after we adjusted for other characteristics.

Table 1. Characteristics of Study Population, According to Caregiver Status^a (N = 3189)

Characteristic	No Caregiver	Household Caregiver	Non-household Caregiver	p Value
	N = 394	N = 1576	N = 1219	
Age (years, mean ± SD)	78.2 ± 9.5	77.7 ± 9.0	80.0 ± 8.5	<.0001
Female gender (%)	65.5	68.4	76.0	<.0001
Non-White race (%)	34.0	59.3	40.4	<.0001
ADL dependence ^b (mean ± SD)	2.1 ± 1.7	3.1 ± 1.6	2.2 ± 1.6	<.0001
IADL dependence ^c (mean ± SD)	7.0 ± 1.5	7.8 ± 0.6	7.3 ± 1.2	<.0001
Bowel incontinence (%)	19.7	31.9	20.9	<.0001
Urinary incontinence (%)	49.7	60.6	49.7	<.0001
Number of chronic conditions (mean ± SD)	6.6	6.7	7.1	.002
Excellent/good self-reported health status (%)	54.4	52.0	53.3	.66
SPMSQ score ^d (mean ± SD)	3.6 ± 3.0	5.0 ± 3.2	3.9 ± 3.0	<.0001
Wandering (%)	10.7	17.1	9.2	<.0001
Verbal disruption (%)	8.4	13.8	7.9	<.0001
Physical aggression (%)	4.2	7.8	3.1	<.0001
Regressive behavior (%)	9.2	10.0	6.2	.0002
Hallucinations (%)	5.8	12.3	7.4	<.0001
Vision impairment (%)	43.7	49.3	47.0	.12
Hearing impairment (%)	35.8	31.8	34.5	.19
Communication impairment (%)	25.6	34.8	21.8	<.0001
Age of program on enrollment (years in operation, mean ± SD)	6.2 ± 3.2	6.0 ± 2.9	6.1 ± 3.0	.30

^aCategorical variables compared via Chi Square; continuous variables compared via ANOVA.

^bActivities of Daily Living. Possible range: 0–5, with higher scores indicating more functional impairment.

^cInstrumental Activities of Daily Living. Possible range: 0–8, with higher scores indicating more functional impairment.

^dShort Portable Mental Status Questionnaire. Possible range: 0–10, with higher scores indicating more cognitive impairment.

Furthermore, none of the caregiver subgroups considered to be at risk for burnout was associated with a greater incidence of nursing home admission, after we adjusted for other baseline characteristics.

The other predictors that were significant in the overall group were age, race, and bowel incontinence. The presence of verbal disruption showed a trend toward a significantly increased risk of nursing home admission. Vision impairment was associated with a lower risk of nursing home admission.

Discussion

Although the majority (87%) of PACE participants have caregivers, just under half of all PACE participants have household caregivers. This is a lower proportion than previously reported in disabled populations, whose rates of living with a caregiver range from 53.9% to 67% (Guralnik, Fried, Simonsick, Kasper, & Lafferty, 1995; McKinlay et al., 1995; U.S. Senate Special Committee on Aging, 1991). Therefore, it may be that the availability of formal services through PACE allows more disabled people to live by themselves than is generally seen under usual care. However, even with the comprehensive services provided by PACE, the subgroup that lives with caregivers are more frail, suggesting that these formal services do not completely compensate for a lack of informal care.

Individuals who had caregivers tended to be more disabled than those who did not, as measured by ADL and IADL impairment as well as incontinence

and hallucinations. Of those with identified caregivers, those who lived with their caregiver were more frail than those who did not, as assessed by most measures, namely, functional status, cognitive status, and presence of behavioral problems, incontinence, and communication impairment. A previous study in usual care also showed an association of increasing disability with increased likelihood of living with a caregiver. In that study, 36% of minimally impaired elders lived with caregivers, as compared with 70% of extremely disabled elders (McKinlay et al., 1995).

Before we adjusted for other characteristics, many care recipient characteristics, namely, age, race, cognition, functional status (ADLs and IADLs), incontinence, verbal disruption, hallucinations, communication impairment, and program maturity were predictive of nursing home admission. The finding that program maturity was not an independent predictor, once other characteristics were adjusted for, suggests that, as programs age, they become better at selecting participants who can benefit from their services.

In the multivariate model, age and race were significantly predictive of time to nursing home admission. These two risk factors have been shown to be consistent predictors of nursing home admission in other populations (Miller & Weissert, 2000). Of all the potentially treatable subject characteristics, bowel incontinence was the only one that was associated with a higher rate of institutionalization in this population, with a hazard ratio of 1.42. It may

Table 2. Predictors of Nursing Home Admission, via Cox Proportional Hazard Regression–Bivariate Analysis (N = 3189)

Characteristic	Hazard Ratio (95% CI)	p Value
Age (per year)	1.03 (1.01, 1.04)	.001
Female gender	0.89 (0.68, 1.16)	.38
Race (relative to White, <i>p</i> value overall .0002)		
African American	0.88 (0.65, 1.21)	.45
Hispanic	1.08 (0.68, 1.70)	.75
Asian/Pacific Islander	0.36 (0.24, 0.56)	<.0001
ADL ^a dependence (per additional)	1.13 (1.04, 1.22)	.002
IADL ^b dependence (per additional)	1.28 (1.08, 1.51)	.004
Bowel incontinence	1.71 (1.32, 2.22)	<.0001
Urinary incontinence	1.43 (1.11, 1.85)	.006
Chronic conditions (per additional)		
Excellent/good self-reported health status	1.02 (0.98, 1.07)	.27
SPMSQ ^c score (per point)	1.07 (1.03, 1.11)	.0007
Wandering	1.36 (0.98, 1.90)	.06
Verbal disruption	2.01 (1.45, 2.77)	<.0001
Physical aggression	1.38 (0.85, 2.22)	.19
Regressive behavior	1.41 (0.93, 2.14)	.10
Hallucinations	1.52 (1.06, 2.18)	.02
Vision impairment	0.85 (0.66, 1.09)	.20
Hearing impairment	1.21 (0.94, 1.56)	.14
Communication impairment	1.38 (1.06, 1.79)	.02
Age of program on enrollment (per year in operation)		
Caregiver present	0.92 (0.88, 0.96)	.0003
	1.07 (0.72, 1.57)	.74

Notes: CI = confidence interval.

^aActivities of Daily Living. Possible range: 0–5, with higher scores indicating more functional impairment.

^bInstrumental Activities of Daily Living. Possible range: 0–8, with higher scores indicating more functional impairment.

^cShort Portable Mental Status Questionnaire. Possible range: 0–10, with higher scores indicating more cognitive impairment.

be that, even with the services that PACE provides, the presence of bowel incontinence remains a stress to those who have caregivers, and also puts those without caregivers at risk for having to give up their independent living situation. Verbal disruption was a borderline predictor, with a hazard ratio of 1.49 and a value of *p* = .06. Similarly, verbal disruption may increase caregiver stress for those who have caregivers, and it may jeopardize the living situation of those without caregivers as well.

Individuals with visual impairment were less likely than those without to be admitted to a nursing home. The individuals in this study population with visual impairment were more likely to be Black or Asian, more likely to be enrolled later in the history of the program, and were less likely to have severe cognitive impairment. These factors may have affected the likelihood that these individuals would be admitted to a nursing home. However, these correlations do not completely explain these findings, because these variables were all adjusted for in the model.

There were substantial differences between sites with respect to the proportion of participants with

Table 3. Predictors of Nursing Home Admission, Adjusting for Caregiver Status, via Cox Proportional Hazard Regression–Multivariate Analysis^a

Predictor	Hazard Ratio (95% CI)
N = 2,996 ^b	
Entire group	
Hazard Ratio	
(95% CI)	
Demographics	
Age (per year)	1.03 (1.01, 1.04)**
Female gender	0.86 (0.63, 1.17)
Race (relative to White, <i>p</i> value .08 overall)	
African American	0.65 (0.44, 0.96)**
Hispanic	0.89 (0.53, 1.51)
Asian/Pacific Islander	0.49 (0.25, 0.98)**
Other	1.35 (0.42, 4.33)
Function	
ADL ^c dependence (per additional)	1.08 (0.98, 1.19)
IADL ^d dependence (per additional)	1.12 (0.94, 1.33)
Bowel incontinence	1.42 (1.03, 1.97)**
Urinary incontinence	0.93 (0.68, 1.27)
Health	
Chronic conditions (per additional)	1.02 (0.98, 1.07)
Self-reported health (vs. excellent, <i>p</i> value overall .72)	
Good	0.89 (0.43, 1.86)
Fair	1.00 (0.54, 1.86)
Poor	1.18 (0.63, 2.23)
Missing	0.92 (0.43, 1.98)
SPMSQ ^e score (per additional point)	1.03 (0.98, 1.08)
Behavior	
Verbal disruption	1.49 (0.99, 2.26)*
Hallucinations	1.13 (0.76, 1.69)
Regression	0.94 (0.58, 1.53)
Physical aggression	0.68 (0.38, 1.23)
Wandering	1.10 (0.75, 1.61)
Sensory impairment	
Vision impairment	0.75 (0.57, 0.99)**
Hearing impairment	1.02 (0.76, 1.36)
Communication impairment	1.01 (0.74, 1.38)
Age of program (per year in operation)	1.04 (0.94, 1.16)
Caregiver present	0.86 (0.49, 1.50)
Caregiver lives separately vs. with subject	1.32 (0.90, 1.95)
Caregiver cut down or quit work	0.83 (0.50, 1.36)
Old vs. young caregiver	1.35 (0.83, 2.21)
Caregiver provides personal care	1.07 (0.76, 1.52)
Spouse caregiver	1.04 (0.64, 1.69)

Notes: CI = confidence interval.

^aAll variables entered into the model are presented. Regressions are stratified by site.

^bN is different from overall group due to missing values of predictor variables.

^cActivities of Daily Living. Possible range: 0–5, with higher scores indicating more functional impairment.

^dInstrumental Activities of Daily Living. Possible range: 0–8, with higher scores indicating more functional impairment.

^eShort Portable Mental Status Questionnaire. Possible range: 0–10, with higher scores indicating more cognitive impairment.

*.5 < *p* < .10.

***p* < .05.

caregivers. In an earlier study, we have described other baseline differences between sites, as well as differences in risk of time to nursing home admission by site. In that study we found that differences in individual site risk of nursing home admission are minimized once patient characteristics are adjusted for, suggesting that the differences in outcome are due to the patients, rather than to programmatic differences (Friedman, Steinwachs, Rathouz, Burton, & Mukamel, 2005).

Once participants were enrolled in PACE, the presence of a caregiver was not associated with the hazard of admission to a nursing home, after we adjusted for multiple measures of frailty and disability at baseline. This finding is different from that of several studies of populations in standard care, in which the presence of more caregiver support and more familiar support is important in reducing the risk of nursing home admission (Miller & Weissert, 2000). It may be that, in standard care, some of the "caregiver effect" is mediated through increased access to formal care, which is not an issue in the PACE model. It should be noted, though, that even in studies of standard care, the effect of a caregiver is not always consistent, and it may relate to the type of informal care rather than just the presence of informal care (Hanley et al., 1990; Miller & Weissert, 2000; Newman et al., 1990).

In addition to examining the relationship between any caregiver and the risk of nursing home admission, we also examined the relationship by type of caregiver. It is possible that different types of caregivers might differentially increase or decrease the risk of institutionalization, such that the overall impact of having a caregiver cannot be observed. We examined several subgroups of caregivers on the basis of the literature of risk factors for institutionalization in usual care.

None of these caregiver subgroups were associated with an increased risk of nursing home utilization in this population, which is different from previously published findings. Individuals who are cared for by caregivers who do not reside with them have been shown to be at higher risk for institutionalization in standard care (Montgomery & Kosloski, 1994). In a study of another community-based long-term-care model, having a caregiver who lived separately was associated with a hazard ratio of 2.32 for being admitted to a nursing home (Tsuji et al., 1995). Many issues may contribute to this finding, including the added stress of commuting in order to provide care, financial issues that may reduce risk with a co-residing caregiver, and the fact that caregivers who reside separately are not usually spouses. The financial issues for the patient should not be as prominent in PACE, which is a capitated program covering nursing home admission once the participant requires it. The presence of a spousal caregiver is adjusted for in the model, and PACE may be able to substitute formal care for a nonhousehold caregiver's care, thereby reducing some of the strains of providing this care.

We also found other subcategories of caregivers to

be unassociated with a greater risk of nursing home admission in the PACE population. In usual care, nonspousal caregivers have been shown to have both a higher prevalence of intention to institutionalize (Morycz, 1985) and a greater incidence of institutionalizing the patient (Kesselring et al., 2001; Montgomery & Kosloski, 1994). McFall and Miller (1992) found that relatives cared for by adult children were more likely to be admitted to nursing homes than those with a primary spouse caregiver. McKinlay and colleagues (1995) found that offspring and other-relative caregivers who resided with the older adult were particularly at risk to experience a negative impact, and those elders whose caregivers experienced a negative personal impact, defined as an effect on sleep, health, leisure, privacy, finances, and household chores, were twice as likely to be institutionalized.

Another group of caregivers previously identified as increasing the risk of nursing home admission are those who provide personal care. In a study by Montgomery and Kosloski (1994), offspring who provided personal care (i.e., bathing, dressing, transferring, or toileting) for their parents were more likely to institutionalize them (hazard ratio = 1.10). This may be related to both the physical and emotional stress caused by providing this type of care.

The risk conferred by having a caregiver who works has shown mixed results in previous studies. In one study (Colerick & George, 1986), individuals who had caregivers who worked full time were at higher risk for nursing home admission, but in another (Montgomery & Kosloski, 1994), spouse caregivers who worked were at lower risk of admitting an individual to a nursing home, and adult child caregivers had no difference in risk if they worked or not.

None of these categories led to statistically significantly increased rates of institutionalization in the PACE model. Thus, among PACE participants with caregivers overall and with caregiver subgroups, the risk of long-term nursing home admission does not change. This is in contrast to evidence from usual care populations of frail older adults, and it raises the question as to why those who are enrolled in PACE are different. Are the PACE participants themselves different, or do the services provided by PACE prevent institutionalization?

One possible explanation is that PACE is able to tailor formal services to compensate for the presence or absence of informal care, as well as for the presence of partial informal care (i.e., care by caregivers that may address some needs but not all). By doing so, PACE is in essence leveling the playing field and eliminating the presence of a caregiver as a factor in determining nursing home entry. PACE also provides services that facilitate care by caregivers through a reduction of caregiver stress and, in turn, caregiver burnout. PACE provides several services, all of which are likely to lower caregiver stress: respite care both through day center attendance as well as periodic inpatient respite care; personal and chore services at home; educational programs for caregivers; and meals on wheels.

Further studies of the specific services provided by PACE to individuals with and without caregivers would provide more insight into which aspects of the program are most important in reducing risk. Currently, PACE cares for a very small proportion of this country's frailest older adults, serving just over 10,000 enrollees nationwide (Centers for Medicare and Medicaid Services, 2004). Learning whether there are particular elements of the PACE model that lead to reduction in risk would help to generate hypotheses as to whether portions of this multifaceted intervention might be "exportable" to standard care. If certain services led to a reduced risk of nursing home admission for those with high-risk caregivers, consideration might be given to broadening benefit coverage to include these services for individuals with these caregivers, in the usual care population.

Another explanation is that this is a self-selected group. It is possible that, because participants and their caregivers enroll in PACE in part because they prefer community-based care to nursing home admission, this wish overrides any additional risk that these caregiver subgroups might pose in usual care. These caregivers may represent a particularly dedicated group of individuals, and the degree to which their level of commitment ameliorates risk is unclear. Further evaluation of the PACE intervention, as outlined above, would also help to answer this question.

In summary, although many of the PACE participants live with caregivers, the proportion is lower than that found in other studies, given their level of frailty. Individuals without caregivers, or those who have caregivers in one of several high-risk categories for burnout, namely, caregivers living separately from the participant, nonspousal caregivers, those who have not cut down or quit work, those over the age of 75, and those who give personal care, are not at increased risk for institutionalization. This suggests that this program, through its multidisciplinary approach to caregiver and patient support, may be meeting needs in this population that, if unmet, may lead to nursing home admission.

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