Primary Caregiver Characteristics and Transitions in Community-Based Care

Susan M. Allen,1 Julie C. Lima,1 Frances K. Goldscheider,1,2 and Jason Roy3

1Brown University Center for Gerontology and Health Care Research, Providence, Rhode Island. 
2Department of Family Finance, School of Public Health, University of Maryland, College Park. 
3Center for Clinical Epidemiology and Biostatistics, University of Pennsylvania, Philadelphia.

Objectives. To identify informal primary caregiver characteristics associated with care transitions of community-dwelling older persons with impairments in daily living activities.

Method. Data for this study were pooled to observe transitions from Wave 1–Wave 2 and Wave 2–Wave 3 of the Second Longitudinal Survey on Aging (LSOA II). The sample includes respondents with at least one impairment in daily living activities and with an informal caregiver at baseline of each transition period (n = 2,990). Primary caregiver transitions to another informal caregiver, to formal care, to a nursing home, or to no care were modeled using multinomial logistic regression.

Results. More than half (54%) of the surviving respondents experienced a care transition for a period of 2 years. Multivariate results indicate that husband and son primary caregivers are more likely to transfer care than wives and daughters, although children caring for same-gender parents were less likely to transfer out of the primary caregiver role than children caring for parents of the opposite sex. Respondents with primary caregivers who are “other” relatives or nonrelatives, who are not coresident with the care receiver, or who are assisted by secondary helpers were at elevated risk for care transitions over the 2-year study period.

Discussion. The results of this study suggest that older persons’ care transitions result from complex informal network dynamics, with primary caregiver gender and relationship to the care receiver playing key roles.

Key Words: Caregiving—Community-based care—Disability.

Despite the decline in disability in the U.S. older population in recent decades (Freedman, Schoeni, Martin, & Cormman, 2007; Manton, Gu, & Lamb, 2006), the projected increase in the size of this population (U.S. Census Bureau, 2008b) combined with gains in life expectancy among people disabled at younger ages (e.g., Lose & Robin, 2007) guarantees that a substantial and likely growing number of individuals will continue to require assistance with everyday activities in order to remain in the community. In addition, the emphasis on community-based long-term care in the Affordable Care Act (P.L. 111-148) will almost certainly result in a major shift in the balance of long-term care service provision from institutions to the community in the future.

It is well known that the family is the “first line of defense” in providing community-based care to older persons as informal care has historically predominated over formal care as the foundation of community-based support to older people with limitations in daily living activities (E. A. Miller, Allen, & Mor, 2009). However, we know little about the dynamics of family care over time or about the characteristics of family caregivers that are associated with stability and change in the primary caregiver role (Gaugler & Teaster, 2006).

The purpose of this study is to examine transitions in primary caregiving experienced by community-dwelling older persons with functional limitations. We identify respondent and primary caregiver characteristics associated with transitions within the informal care network to formal care, including institutionalization, as well as to no care. Our framework is Litwak’s Task-specific Model of Helper Selection (Litwak, 1985) that we modify to add considerations of caregiver gender to his discussion of relationship to the care receiver, thus providing a broader and more dynamic theoretical basis for understanding caregiver stability over time. Results of this research are intended to inform current policies about the family care foundation upon which health reform efforts to move long-term care to the community will build.

Background

There are few longitudinal studies that have examined care transitions within the informal care network. Several studies conducted in the late 1980s and early 1990s focused on caregiving network expansions and/or change in composition (B. Miller & Furner, 1994; B. Miller & McFall, 1991; Stoller & Pugliesi, 1988) but reported little on the characteristics of caregivers or networks that are associated with...
stability versus change over time. More recently, research using pooled data from Waves 1–5 (1992–2000) of the Health and Retirement Survey examined adult child caregivers aged 51–61 who had siblings and found that more than one quarter of adult child primary caregivers changed (Szinovacz & Davey, 2007).

In contrast to the relatively small number of studies focusing on care transitions within the informal care sector, a substantial body of research has focused on the transition from informal caregiver to nursing home placement among older individuals with Alzheimer’s disease and other chronic conditions. Most studies of transitions from an informal caregiver to the nursing home focus on caregiver stress and burden (e.g., Gaugler, Yu, Krichbaum, & Wyman, 2009).

Research on factors associated with use of formal, or paid, home care seldom report initiation of paid care as a transition from informal to formal primary caregiver. In fact, most studies have found that paid care is most often a supplement (more care) or complement (technical care), rather than a substitute for family care, added to the caregiving network when older persons’ needs exceed the ability of informal caregivers to meet them (e.g., Penning, 2002; Tennstedt, Harrow, & Crawford, 1996). An exception is paid care used by persons who live alone and lack an informal helping network (Kadushin, 2004). Notably, a number of studies have found the initiation of paid care to be a precursor to nursing home placement (Jette, Tennstedt, & Crawford, 1995; McCann et al., 2005).

Given the dearth of research reporting caregiver characteristics predictive of care transitions, we inform our hypotheses with the task-specific model of helper selection developed by Litwak and colleagues (Litwak, 1985; Litwak, Messeri, & Silverstein, 1990; Messeri, Silverstein, & Litwak, 1993). To date, the task-specific model has been useful in cross-sectional studies in advancing our understanding of patterns in the helping networks of older persons who reside in the community with long-term care needs. We extend this theory to include caregiver gender, thus transforming a relatively static theory into a framework that is useful for understanding the dynamics of informal care over time. Our study is the first, to our knowledge, to employ this model in the context of longitudinal data.

The Task-Specific Model of Helper Selection

The task-specific model posits that the selection of helpers for the frail elderly adults is based on the fit between services required and the structural features of primary groups, as well as of formal service organizations (Litwak, 1985). In the situation of caregiver selection for an older person with functional limitations, key characteristics that may differentiate selection of one member of a primary group, that is, family members, friends, and neighbors, over another are length of commitment to care and physical proximity to the person requiring care. According to Litwak’s theory, a spouse, who has a long-term commitment to, and who is most proximate to, the older person is theoretically best suited to fill the caregiver role when need for care arises, although a spouse’s poor health may force choice of the next best “match.” Adult children are typically as likely as a spouse to have a long-term commitment to their parents, although commitment may be compromised by other responsibilities that are common in middle age, including juggling employment and perhaps care of their own children. Additionally, adult children are much less likely to be coresident with their parents than in the past (Ruggles, 2007). Thus, there are contingencies on the individual level that may nullify the otherwise normative features of primary group relationships that determine the “best fit” of caregiver to care receiver.

Of all primary group members, nonkin are the poorest match with the primary caregiving role, given that most nonkin are unlikely to be able and/or willing to make a long-term commitment to a person with care needs (although clearly there are exceptions). Indeed, the limited literature in this area suggests that friends and neighbors are least likely to provide activity of daily living (ADL) assistance but usually limit their help to occasional tasks and errands (Barker, 2002; Nocon & Pearson, 2000). Relatives other than a spouse or adult child are likely to vary in long-term commitment and proximity to the person requiring care, and thus as a group, fall somewhere between adult children and nonkin in their fit with long-term caregiving for older persons with impairments.

Patterns of informal care observed in samples of the community-dwelling elderly adults are quite consistent with the task-specific model (Spillman & Pezzin, 2000; Wolff & Kasper, 2006), with spouses and adult children predominant, although other relatives are represented at lower levels as primary caregivers, and nonkin are least prevalent in this role. It is our hypothesis that the same factors that influence patterns of primary caregiver selection will also be associated with stability versus change in the primary caregiver role over time, with one important addition.

Incorporating Gender Into the Task-Specific Model

The task-specific model characterizes situations in which a “mismatch” between a primary caregiver’s characteristics and the services required by the care receiver may result in poor quality care, and thus, potentially compromised health status or quality of life for the care receiver (Allen & Ciambrone, 2003; Messeri et al., 1993). A poor match may also have negative implications for the caregiver, for example, undue stress. Most relevant to our study, a mismatch may result in the primary caregiver’s exit from the caregiving role, ideally, but not necessarily, leading to a care situation that is a better match with the older person’s needs.

However, it is our contention that relationship to the care receiver does not have sufficient explanatory power when
examining factors related to caregiver stability versus change over time. As discussed earlier, contingencies on the individual level may override the theoretical best match with an older person’s long-term service needs. We argue that caregiver gender is a characteristic of primary group members that systematically contributes to caregiver-care receiver fit. Gender is absent in helper selection theory, despite the fact that gender differences in the distribution of caregivers to older persons are glaring. In fact, it has long been recognized that the vast majority of caregivers are women, and when men provide care, most do so quite differently from women. Specifically, male caregivers are less likely to provide personal care and housework than are female caregivers and are more likely to be secondary rather than primary caregivers (e.g., Navaie-Waliser, Spriggs, & Feldman, 2002; Pinquart & Sorenson, 2006).

In the context of the task-specific model, some men may consider themselves to lack the “technical knowledge” (i.e., of female-linked tasks) required of a primary caregiver. They are thus unable to make a long-term commitment to providing care because they experience the caregiving role as incongruent with their gender socialization (Allen, 1994). This interpretation is consistent with women’s continued prominence as caregivers (e.g., Wolff & Kasper, 2006) and the finding of Szinovacz and Davey (2007) that daughters are significantly less likely to transition out of caregiving than sons. Thus, we hypothesize that inconsistencies between the caregiving role and many husbands’ and sons’ gendered identities will result in a higher likelihood of primary caregiver transition than when wives and daughters fill the primary caregiver role. Specifically, we expect that husbands will be more likely than wives to transfer their spouse’s care to another member of the informal sector, or lacking other potential caregivers, to formal care. Similarly, we expect sons, but not daughters, to be more likely than wives to transfer care to another family caregiver, or to the formal sector, including to a nursing home.

The gendered nature of the family has another dimension as well, rooted in gender asymmetries of intimacy. Personal care often involves the most intimate of tasks, including bathing, dressing, and toileting. Sons may have difficulty crossing cultural boundaries of intimacy in order to provide such care for their mothers, and daughters may be uncomfortable as caregivers for their fathers (Rossi & Rossi, 1990). This is supported by a study of 4,371 older persons with impairment in daily life activities showing that parents are more likely to receive care from children of the same gender (Lee, Dwyer, & Coward, 1993). We hypothesize that this “gender preference” will also influence care transitions such that children (both sons and daughters) will be less likely to transfer care to others when the parent requiring care is of the same gender.

We also hypothesize that primary caregivers who are relatives other than a spouse or child will be less stable in the caregiving role than spouses or children regardless of gender because they lack the long-term commitment required by older persons who may live with chronic conditions and impairments for many years, even decades. It is likely that some relatives serve as primary caregiver by default because no one else is immediately available to take on this role, or because the need is perceived to be temporary, or because of their proximity to the older person who requires care. Other relatives will thus be more likely to transfer caregiving responsibility to another member of the informal network over time, or to the formal sector. We expect the same results for nonrelatives, although we expect the relationship effect on transitions to be stronger than for other relatives. Additionally, we hypothesize that older persons will be at risk of discontinuation of care because a nonkin caregiver may perceive there to be no alternatives.

Secondary caregivers, as helpers for the primary caregiver, may improve the fit of the caregiving situation by providing sufficient support to enable keeping the older person at home. The involvement of multiple family members in care also provides the opportunity for “turn taking,” that is, transitioning between primary and secondary caregiver roles to avoid burnout. Indeed, in adjusted analyses, Szinovacz and Davey (2007) observed an exchange of one sibling for another. Thus, we hypothesize that respondents with secondary informal caregivers are more likely to transition to a different informal primary caregiver than are respondents without informal secondary caregivers at baseline. Paid secondary caregivers, on the other hand, represent an initial step into the formal sector that often signals an increasing severity of the care recipient’s condition and will be predictive of nursing home placement. Finally, based on the importance of proximity to a good match between primary caregiver and the older person’s ongoing needs (Messeri et al., 1993; Tennstedt, Crawford, & McKinley, 1993), we hypothesize that respondents whose primary caregiver is not coresident will be at elevated risk for care transitions. Specifically, those who live alone may be at risk for nursing home placement or complete care cessation.

**Method**

**Data**

This research was based on data from the Second Longitudinal Survey on Aging (LSOA II). The Second Supplement on Aging (SOA II), the baseline interview of the LSOA II, was fielded by the National Institute on Aging and the National Center for Health Statistics as a supplement to the 1994 and 1995 National Health Interview Surveys (NHIS), 10 years after the original SOA, with a new cohort of community dwelling elders aged 70 and older. The LSOA II is a prospective study using a complex multistage probability sampling design, yielding a nationally representative sample of noninstitutionalized civilians aged 70 and older at the time of the baseline interview. Follow-up interviews were
conducted in 1997–98 (Wave 2) and 1999–2000 (Wave 3), with the baseline interview conducted in person and the follow-ups by phone. The Second Supplement on Aging data file also includes information from the 1994 NHIS Core interview, the 1994 NHIS Access to Care Supplement, and the 1994 Phase 1 Disability Supplement. However, the majority of the SOA II data file is from the SOA II interview. For more information about sample design and attrition, see National Center for Health Statistics (2002).

Study Sample

Because the focus of this research is on the characteristics of informal primary caregivers associated with stability versus change in the caregiving role, individuals were eligible for our study if they met the following inclusion criteria at either Wave 1 or Wave 2: (a) They reported having difficulty performing at least one ADL or instrumental activity of daily living (IADL), (b) they received assistance from an informal primary caregiver for those ADL/IADL tasks, and (c) they were interviewed during the subsequent wave or were successfully identified as having died. Of the 9,447 respondents to the SOA II, 3,124 met the first two criteria in one or both waves, 611 of whom were lost to follow-up for reasons other than death and therefore did not meet the third criterion. Of the 2,513 who met all the three study criteria, 594 met them at both Waves 1 and 2, and therefore were included in our sample twice, resulting in a sample size of 3,107 observations. Finally, 117 observations were dropped due to incomplete information, bringing our final sample to 2,990 observations among 2,425 unique individuals. For ease of discussion in the remainder of the paper, we refer to the 2,990 observations as “respondents” or “individuals.”

Measures

The dependent variable for these analyses was type of care transition (if any) between pairs of consecutive waves, that is, Wave 1–Wave 2 and Wave 2–Wave 3. At all three time points, respondents were asked to name their primary caregiver and the relationship of the named primary caregiver to them. This constructed variable compared primary caregiver status across each 2-year transition period and consisted of six categories: (a) no change in primary caregiver from baseline to follow-up, (b) transition to another informal primary caregiver, (c) transition to a formal primary caregiver, (d) transition to an institution, (e) transition to no care, and (f) death. Death is considered to be a competing outcome with other possible transitions and is included to minimize bias associated with attrition. “No change in primary caregiver” serves as the reference category for this variable in multivariate analyses.

The independent variables of primary interest to this study were the primary caregiver gender and relationship to the care receiver. We combined the relationship of the caregiver to the respondent and the caregiver’s gender into the following groups: husband, wife, daughter, and son. Because the categories other relative and nonrelative are nonnormative among primary caregivers, we did not further distinguish these groups by gender. It should be noted that rates of transition within the informal care system are likely to be underestimates in this study because we are unable to identify a transition that occurs between informal caregivers of the same gender and relationship to the respondent.

Dichotomous indicators of secondary helpers were also included, that is, presence of one or more secondary informal helpers in the network (yes/no) and presence of one or more secondary formal helpers (yes/no). A three-category variable captured the primary caregiver’s coresidence with the respondent, combined with the respondent’s living arrangements. Possible responses were (a) primary caregiver and the respondent coreside, (b) they do not coreside but respondent lives with others, and (c) respondent lives alone.

Several sociodemographic characteristics of the respondent were controlled in the analyses. These were age (less than 80 vs. 80 or older), gender, race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic), and level of education (less than high school, high school graduate, more than high school).

Illness and impairment severity have been shown to be strong predictors of transitions to a nursing home (E. A. Miller & Weissert, 2000) as well as strong predictors of caregiver burden (e.g., Molyneux, McCarthy, McEniff, Cryan, & Conroy, 2008; Vincent, Desrosiers, Landreville, Demers, & BRAD Group, 2009). Three variables were included: baseline number of ADL difficulties (range 0–6; Katz & Akpom, 1976), baseline number of IADL difficulties (range 0–7; Lawton, 1971), and an indicator of whether the sample person responded to the interview himself or via a proxy respondent. If a proxy was used, interviewers further indicated whether the proxy was used due to the sample person’s illness or to cognitive impairment. ADLs included in this study were bathing or showering, dressing, eating, getting in or out of bed/ chairs, walking, and using or getting to the toilet. IADLs included meal preparation, shopping for groceries, managing money, using the telephone, doing heavy housework, doing light housework, and managing medications.

Finally, we included an indicator of whether the observation began in Wave 1 or Wave 2 because respondents who entered the study with a caregiver are likely to have had a longer duration of need for help than respondents who acquired a caregiver over the course of the study, and thus, a potentially higher risk for care transition.

Data Analyses

Multinomial logistic regression in Stata 11.1 was used to determine factors related to four possible transitions in care, and also death as a competing outcome, relative to stability.
Multinomial logistic regression is appropriate when the dependent variable of interest is a nonordinal variable with more than two categories. To test our “gender preference” hypothesis, we conducted an additional analysis that examined the interaction of the gender of the child caregiver and the gender of the parents on care transitions, using the subsample of care recipients being cared for by their children ($n = 1,175$).

We used svy: procedures within Stata for all descriptive and multivariate analyses in order to adjust for the complex survey design of the LSOA II, assigning values for the final weight, primary sampling unit and stratum in accordance with Method 1 provided by National Center for Health Statistics for use with these data (National Center for Health Statistics, 2002). We further adjusted the final weight (a) to account for loss-to-follow-up of our eligible sample across waves and (b) to account for repeated measures, given that individuals could enter the study twice. Consequently, the subgroup in our cohort is nationally representative.

### Results

#### Sample Description

Table 1, Column 1, presents the weighted distribution of respondent and caregiver characteristics at baseline. The distribution of possible transitions over time by each of these characteristics is presented row wise. Overall, 32%...
of respondents reported the same primary caregiver 2 years later, 38.8% of respondents experienced a care transition, and 29.2% died between survey Waves. Considering survivors only, more than half (54.2%) transitioned to a new care situation over a 2-year period.

### Caregiver and Respondent Characteristics Predictive of Transitions

The results of the multinomial logistic regression model are presented in Table 2. Weighted results are presented as relative risk ratios (RRR) with 95% confidence intervals.

### Caregiver Characteristics

Results indicate that respondents with wives and daughters as primary caregivers at baseline had similar risks for each type of care transition, with one exception; respondents cared for by daughters have only approximately half the risk of transitioning to no care as respondents cared for by wives. Respondents cared for by husbands or sons had more than three times the risk of transferring care within the informal sector relative to respondents cared for by wives, and those cared for by sons had nearly three times the risk of transitioning to a formal caregiver than those cared for by wives.

Weighted results of our subanalysis of the interaction of the gender of the child caregiver and the gender of the parents on care transitions revealed only one transition that demonstrated “gender preference.” Specifically, there was a significant interaction (p < .01) influencing parents’ care transitions over time to another informal caregiver, relative to no change. The reference group for the interaction was daughters caring for mothers (0, 0), with (1, 1) assigned to sons caring for fathers. Compared with daughters caring for mothers, both daughters (RRR = 2.09) and sons (RRR = 2.33) caring
Table 3. Multinomial Regression of Transitions in Care from Baseline to 2-Year Follow-up Among Respondents With a Son or Daughter Informal Caregiver at Baseline: Interaction of Child and Parent Gender (weighted data)

<table>
<thead>
<tr>
<th>Transition to (other) informal versus no change</th>
<th>Transition to formal caregivers versus no change</th>
<th>Transition to institution versus no change</th>
<th>Transition to no care versus no change</th>
<th>Transition to death versus no change</th>
</tr>
</thead>
<tbody>
<tr>
<td>RRR (95% CI)</td>
<td>RRR (95% CI)</td>
<td>RRR (95% CI)</td>
<td>RRR (95% CI)</td>
<td>RRR (95% CI)</td>
</tr>
<tr>
<td>Care recipient is male (father)</td>
<td>2.09 (1.01, 4.38)*</td>
<td>1.28 (0.41, 4.02)</td>
<td>0.98 (0.36, 2.61)</td>
<td>1.56 (0.77, 3.16)</td>
</tr>
<tr>
<td>Primary CG is son</td>
<td>3.62 (1.91, 6.88)**</td>
<td>2.25 (1.18, 4.28)*</td>
<td>1.70 (0.99, 2.92)</td>
<td>1.55 (0.94, 2.56)</td>
</tr>
<tr>
<td>Son= father</td>
<td>0.61 (0.13, 2.89)</td>
<td>0.69 (0.15, 3.06)</td>
<td>0.74 (0.21, 2.63)</td>
<td>0.86 (0.33, 2.27)</td>
</tr>
<tr>
<td>Model F(100, 87) = 4.36; p &lt; .000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes. CG = caregiver; RRR = The model also controls for all covariates used in Table 1.
*p < .05; **p < .01; ***p < .001.

for parents of the opposite gender were more likely to transfer care to another informal caregiver. In addition, sons caring for fathers were less likely than daughters caring for mothers to transition to another informal caregiver (RRR = 0.78). See Table 3.

As hypothesized, respondents whose primary caregivers were “other” relatives or nonrelatives had higher risk of transitioning to another primary informal caregiver over time, relative to those with a wife as primary caregiver. Additionally, respondents cared for by nonkin had higher risk of transitioning to a formal primary caregiver. Respondents with other relative or nonrelative caregivers were also at higher risk of death over the 2-year period.

Also consistent with our hypotheses are the findings that respondents with secondary informal helpers at baseline had increased risk of transitioning to a different informal primary caregiver. Additionally, respondents with secondary formal helpers at baseline had higher risk of transitioning to a formal primary caregiver, and also had higher risks of institutionalization and death. Finally, respondents with secondary formal helpers had reduced risk of transitioning to no care, relative to respondents who did not have secondary formal helpers at baseline.

Relative to respondents who lived with their primary caregiver at baseline, respondents who lived with others were at higher risk of transitioning to another informal primary caregiver at follow-up, and respondents who lived alone at baseline had more than twice the risk of transitioning to a nursing home over the 2-year follow-up period. Additionally, respondents who lived with others and those who lived alone were at significantly higher risk of transitioning to a formal primary caregiver and were also at elevated risk of transitioning to no care than respondents who lived with their caregiver.

Respondent Characteristics

Of the respondent sociodemographic characteristics included as controls in this analysis, results were as expected, with older age, number of ADLs, and cognitive impairment predictive of higher risk of transitions to the nursing home and to death and with the exception of old age, lower risk of transition to no care. Sociodemographic characteristics other than age had little effect on study outcomes; however, respondents who were study-eligible at Wave 1 were at higher risk for all care transitions, with the exception of transition to another informal caregiver, than respondents who became eligible at Wave 2.

Finally, recognizing that the variables husband/wife as caregiver, living arrangement, and care receiver gender present potential problems of multicollinearity, we removed care receiver gender and living arrangement from our final model to determine their effect on estimates of the probability of transitions associated with the indicator of husband versus wife as caregiver. We found little change, with the exception of transition to death, which changed from 1.27 (ns) in the original model to 0.58 (p < .01) when both variables are removed. Because transition to death is not of theoretical importance to this paper, our final model includes all three variables.

Discussion

We examined transitions in care experienced by a national sample of persons aged 70 and older who received disability-related assistance in daily living activities from an informal primary caregiver at baseline of each 2-year transition period between survey waves. We found that more than half of the surviving respondents had transitioned to a new care situation, or to no care, 2 years later. As we hypothesized, older persons with wives and daughters as primary caregivers were not different in their transition risks (with one exception), although women cared for by husbands or sons were more likely to transition to another member of the informal network, and parents cared for by sons to a formal primary caregiver. The consistency of these findings with findings from cross-sectional studies of gender differences in caregiving suggests that men’s socialization may not prepare them well for the primary caregiver role, although some who transfer care may continue to help with tasks that are congruent with their life experience. Because men report less caregiving burden than women (Pinquart & Sorensen, 2006), interventions that target burden may be missing the mark in terms of their ability to promote men’s stability in the primary caregiver role. However, contrary to our hypothesis, risk of nursing home placement was
not elevated for persons cared for by husbands or sons in this study.

Our finding that sons and daughters are more likely to transition care to another family member when caring for a parent of the opposite gender confirms the “gender preference” pairing of caregiver to care receiver reported by Lee and colleagues (1993), and suggests that issues of intimacy may interfere with sons’ ability to serve as primary caregivers for their mothers, and daughters for their fathers, when ADL help is needed. Unexpectedly, sons caring for fathers were less likely to transition care than daughters caring for mothers.

Our hypotheses regarding other relatives and nonkin were mostly supported by the results. The magnitude of the effects of nonrelatives and other relatives on care transitions to other members of the informal network or to formal care suggests that in most cases it may not be feasible to expect nonnuclear family members to provide care to older persons for extended periods of time. The fact that persons cared for by other relatives and nonkin were at high risk of death over the 2-year follow-up interval suggests that these nonnuclear family members may step in to provide care in a situation of high need when nuclear family members were not available.

As we expected, respondents with secondary informal caregivers at baseline had elevated odds of transitioning to another member of the informal care network, suggesting that more than one caregiver may allow for taking turns as primary caregiver to a loved one in need. Turn-taking may be a strategy to avoid any one caregiver experiencing burn-out, or may occur in response to burnout, as the next step taken to avoid nursing home placement. However, in this study, only 34% of respondents had secondary family caregivers, a dramatic decrease from prior decades (Wolff & Kasper, 2006), and thus, the majority of caregivers were less likely to have family “alternates” to relieve them from care responsibilities.

Respondents with formal secondary caregivers were at higher risk for institutionalization, perhaps due to more intensive care needs that may not be adequately controlled through available data. Our finding that persons with secondary caregivers are at elevated risk for death supports this interpretation. Although our findings do not suggest that informal caregivers cease providing care upon initiation of formal services, they do suggest elevated odds that the role of formal care shifts from a supporting to primary caregiving role over time. This result, as well as the elevated risks for primary caregiver transitions to formal care by sons and nonrelatives observed in this study, points to some substitution of formal for informal care.

Living with others but not the primary caregiver is also associated with elevated odds of transition to another informal caregiver, which may occur when caregiving from outside the home proves to be too demanding, or when an older person recovers sufficiently so that care reverts to an in-house caregiver, such as a frail spouse who may only be able to meet minimal care needs. Not surprisingly, living alone is associated with increased odds of nursing home placement in this study, as it is in previous studies (Rudberg, Sager, & Zhang, 1996; Yaffe et al., 2002), although it is likely that persons living alone prior to placement make up a substantial proportion of the “low care” nursing home population (Mor et al., 2007). Given that nearly 30% of the aged 65 and older U.S. population lives alone (U.S. Census Bureau, 2008a, American Community Survey), this vulnerable subgroup poses particular challenges for current nursing home diversion and deinstitutionalization efforts supported by health reform. The magnitude of the effect of caregiver residence on cessation of care suggests that living alone or with persons other than the primary caregiver may also be a flag for unmet need (Allen & Mor, 1997; Desai, Lentzner, & Weeks, 2001).

Study Strengths and Caveats

There are many strengths of this study, including a more comprehensive look at informal primary caregiver transitions than has been published to date, in a national sample of older persons who live in the community with care needs. Further, we model a full range of policy-relevant care transitions. However, there are also several caveats, including our inability to identify transitions within the informal network when the gender and relationship to the person receiving care are the same. This limitation may partly account for the lower rate of adult child primary caregiver transitions within the informal sector in our study relative to the study of Szinovacz and Davey (2007), although this difference is also likely attributable to substantial differences in the studies’ samples. Our inability to capture same gender transitions within the family is not a major limitation from a theoretical standpoint because according to the task-specific model, people of the same relationship are similar in their propensity to provide care. We argue that this is also true in regard to gender. However, we are not able to capture the extent of turn-taking within the informal network, although some proportion is captured by our indicator of secondary informal caregivers.

Further, the 2-year intervals between the three waves of the LSOA II may be an additional source of underestimation, because it is likely that we have missed transitions in care that occurred between waves. Shorter intervals between waves and/or questions to capture transitions retrospectively would enable a more complete picture of primary caregiver stability and change over time. In addition, inclusion of more information about caregivers would help further understanding of the causality underlying caregiver transitions, specifically those characteristics that represent often conflicting responsibilities and/or circumstances that result in family members exiting the caregiving role, for example, caregiver health, work status, and number of dependent children.
In conclusion, our study expands the scope of prior investigations of stability and change in informal care. It is also the first to apply the task-specific model of Litwak and colleagues in longitudinal research and has enhanced the usefulness of this model by adding considerations of caregiver and care recipient gender. We have found that a son is less stable than a daughter when caring for his parents unless he is caring for his father, in which case he is most tenacious in his care. Clearly, the predictive validity of indicators of caregiver relationship to respondent care transitions is limited without considering gender, particularly when applied to the context of caregiving by members of the nuclear family in which gender roles and gender asymmetry in intimacy between parents and children operate most strongly.

Although it is beyond the scope of this study to determine whether and when primary caregiver stability versus change is beneficial for the care receiver, our multivariate results suggest that some proportion of the transitions to formal care, to the nursing home, and to no care may be indicative of a lack of congruence with older persons’ needs. There is a need to continue to broaden our understanding of the dynamics of informal care transitions, given that, the family is the foundation upon which current federal and state efforts to “rebalance” long-term care builds. The results of this study suggest that some caregiver characteristics signal likely short tenure in the caregiving role; thus, states should consider a monitoring mechanism in such situations and be prepared to intervene with enhanced services or new care arrangements to ensure that the needs of older persons receiving community-based care are met.

FUNDING
This work was supported by a grant from the National Institute on Aging (5R01 AG22073).

ACKNOWLEDGMENTS
We wish to thank Pedro Gozalo, PhD, for his help in determining the appropriate weights for our subsample of the LSAS II. We also thank three anonymous reviewers for their helpful comments. S. M. Allen designed the study and wrote the majority of the first draft and subsequent revisions. J. C. Lima conducted all data analyses and contributed to the design and writing of the paper and revisions. F. Goldscheider contributed to writing the paper and revisions and also contributed to study design, particularly the “gender preference” analysis. J. Roy provided statistical expertise for multivariate analyses.

CORRESPONDENCE
Correspondence should be addressed to Susan M. Allen, PhD, Center for Gerontology and Health Care Research, Program in Public Health, Brown University, Box G-S121-6, Providence, RI 02912. E-mail: susan_allen@brown.edu.

REFERENCES


