Long-Term Adaptation to Institutionalization in Dementia Caregivers

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Purpose: Longitudinal research in dementia has acknowledged the importance of transitions during the course of family caregiving. However, long-term adaptation to institutionalization has received little attention. This study attempts to describe caregivers' adaptation (changes in stress, well-being, and psychosocial resources) to placement up to 4 years following institutionalization. **Design and Methods:** Using data from the Caregiver Stress and Coping Study, this analysis constructed four longitudinal panels, each consisting of a preplacement assessment and either two (n = 146), three (n = 109), four (n = 75), or five (n = 38) waves after placement. We used growth curve models to examine longitudinal trajectories of adaptation in various measures of stress, global well-being, and psychosocial resources. **Results:** The findings suggested sharper decreases in stressors (e.g., role overload) and indicators of negative mental health in the shorter term panels. However, more significant intraindividual variation existed in caregivers' adaptation to placement in the longer term panels (four and five waves of postplacement). *Implications:* There is relative stability in caregiver long-term adaptation to institutionalization. However, the variability in adaptation emphasizes the need to target postplacement clinical interventions to families most at risk for negative outcomes during the transition to institutional care.

Key Words: Nursing home placement, Nursing home admission, Alzheimer's disease, Family caregiving, Informal long-term care

Institutionalization is a major transition for caregivers of older people with significant disabilities (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Family caregiver stress often emerges as a significant predictor of nursing home (NH) admission, which suggests that family members and their reactions to care provided in the community are important contributors to whether institutionalization occurs (e.g., Yaffe et al., 2002). It is widely assumed that placement will alleviate the burden of care, and past research has largely focused on predictors of placement rather than on how caregivers experience the transition (e.g., see reviews by Dunkin & Anderson-Hanley, 1998; Fisher & Lieberman, 1999). Placement, however, does not end the caregiving role. Instead, caregivers often renegotiate their role within the context of the institutional setting (Gaugler, 2005). Although relieved of primary responsibility for assisting their relative, caregivers remain involved in care in a variety of ways, including visiting the facility (sometimes as often as once a day), providing social support, and even assisting their relative with activities of daily living (Aneshensel et al., 1995; Gaugler, 2005; Gaugler, Zarit, & Pearlin, 2003a). Family caregivers often interact with staff and advocate for better care for their relatives, and they may find themselves in conflict over how best to provide care. These activities, along with financial pressures to pay for NH care, can be stressful for many caregivers (Gaugler, Anderson, Zarit, & Pearlin, 2004; Zarit & Whitlatch, 1992). Although less explored, psychological processes such as guilt, resentment, unresolved problems between the caregiver and recipient, and conflict with family and friends over the placement decision may also contribute to the caregiver's postinstitutionalization stress.

Given these observations, it should not be surprising that the few studies that have focused on the transition that caregivers make from home care to an institutional setting have found that placement is not

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associated with an average reduction in emotional distress. Schulz and colleagues (2004), for example, followed people up to 18 months after placement and found that feelings of depression and anxiety were as high as before institutionalization. These effects were greater for spouses who had placed their husbands or wives. Zarit and Whitlatch (1992) also found no change up to 1 year after placement in caregivers' emotional distress, including depressive and anxiety symptoms and anger. In contrast to Schulz and colleagues (2004), however, Zarit and Whitlatch reported that the transition had similar effects for husbands, wives, and daughters who were primary caregivers. They also noted that although the overall sample had no mean change, some individuals improved and others worsened (see also Aneshensel et al., 1995). About one half of caregivers had elevated scores for emotional distress 1 year after placement. Caregivers with better emotional well-being postplacement had lower care-related stressors preplacement and a further decrease in these stressors over the transition period. Higher competence in the caregiving role but lower mastery were associated with better emotional outcomes (Aneshensel et al., 1995). Duration of time since placement was associated with improved outcomes.

Although a rapid decline and death of the patient sometimes follows placement (e.g., Aneshensel, Pearlin, Levy-Storms, & Schuler, 2000; Aneshensel et al., 1995; Mitchell et al., 2004), some people may live in a NH for several years. During that time, the majority of caregivers maintain their initial levels of involvement in the NH (Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). Little is known, however, about how ongoing involvement might affect caregivers' psychosocial resources or emotional well-being. One possibility is that prolonged stress associated with ongoing care and seeing one's relative continue to decline would result in deterioration in the caregiver's resources and well-being. In contrast to this "wear-and-tear" model, it is possible that caregivers will adapt over time, learning new coping strategies or distancing themselves emotionally from their relative. Investigations of long-term care by families in the community have reported evidence both for wear and tear and for adaptation (Pot, Deeg, & van Dyck, 1997; Townsend, Noelker, Deimling, & Bass, 1989). Another possibility consistent with findings on short-term adaptation to placement (Aneshensel et al., 1995; Zarit & Whitlatch, 1992) is that caregivers could differ in their trajectories, with some improving over time and others worsening.

The present study used a unique, longitudinal sample of caregivers, all of whom were caring for a relative with dementia at home at the start of the study (Aneshensel et al., 1995). Researchers followed caregivers at yearly intervals, including after institutionalization. The current study followed caregivers who placed a relative for up to 4 years after admission. Specifically, we focused on changes in

psychosocial resources and well-being following NH admission. We were interested in whether trajectories in resources and well-being follow a pattern of decline (wear and tear) or adaptation, or if individual variability characterize changes over time. These descriptive analyses provide the first comprehensive assessment of the impact of long-term NH placement on caregivers.

Methods

Caregiver Stress and Coping Study (CSCS)

Subsequent analyses relied on data from the CSCS (see Aneshensel et al., 1995). The CSCS was a prospective longitudinal study of dementia caregiving. Although the CSCS is approximately 15 years old, a unique aspect of the study design was the continued administration of interviews to primary informal (i.e., unpaid) caregivers of individuals with dementia following key transitions, such as institutionalization or the death of the care recipient. Participants in the CSCS were recruited from Alzheimer's Association chapters in the Los Angeles and San Francisco areas and from the Family Caregiver Alliance in the San Francisco area. Additional eligibility criteria were as follows: (a) the person with dementia had a confirmed physician diagnosis of Alzheimer's disease or an associated dementia; and (b) the caregiver was a spouse, adult child, or daughter-in-law or son-in-law of the person with dementia. In all, 555 caregivers who provided assistance to relatives in a home setting participated in the baseline CSCS interviews. Researchers administered yearly protocols on an annual basis over a 5-year period, resulting in up to six waves of data for each participant.

The objective of the present study was to examine adaptation following the NH transition for dementia caregivers at a minimum of 1 year postplacement and up to 4 years postplacement. The CSCS included 146 caregivers with a minimum of 2 years of postplacement data, and it was from these participants that we constructed the longitudinal panels. Table 1 presents sociodemographic data for these individuals (under the "2-Wave Panel" column). Consistent with other research on informal long-term care, less than a third of the caregivers in the sample were men. Almost half of all caregivers were spouses. On average, caregivers had received 14 years of formal education, were mostly Caucasian (80.1%), and indicated a high annual income. Caregivers had provided almost 3 years of care and were nearly 60 years of age upon enrolling in the CSCS, whereas care recipients were nearly 75 years of age.

Each panel for the current study included *preplacement data* (or information from the at-home interview prior to institutionalization) and two, three, four, or five waves of postplacement data. The construction of the postplacement panels resulted in the following subsamples: 2-wave postplacement

Table 1. Panel Comparisons

Variable	2-Wave Panel $(N = 146)$	3-Wave Panel $(N = 109)$	4-Wave Panel $(N = 75)$	5-Wave Panel $(N = 38)$
Sociodemographic characteristics				
Male care recipient (%)	32.2	29.4	32.0	28.9
Male caregiver (%)	30.1	32.1	36.0	34.2
Spouse caregiver (%)	49.3	46.8	50.7	47.4
Duration of care (years), M (SD)	2.86 (2.13)	2.76 (2.14)	2.60 (1.95)	2.90 (2.23)
Caregiver education (years in school), $M(SD)$	14.19 (2.50)	14.31 (2.47)	14.23 (2.79)	13.97 (2.70)
Caregiver income (3-item scale), M (SD)	2.52 (0.94)	2.53 (0.96)	2.47 (0.94)	2.39 (0.98)
Caregiver is Caucasian (%)	80.1	82.6	78.7	76.3
Care recipient age, M (SD)	74.71 (8.60)	74.43 (9.07)	74.39 (9.18)	74.00 (9.19)
Caregiver age, M (SD)	59.36 (13.45)	58.35 (13.99)	59.28 (14.38)	58.84 (15.30)
Primary subjective stressors, M (SD)				
Role overload, preplacement	2.68 (0.89)	2.61 (0.87)	2.61 (0.86)	2.55 (0.87)
Intrapsychic strain, M (SD)				
Loss of self, preplacement	1.89 (0.79)	1.83 (0.80)	1.80 (0.81)	1.74 (0.81)
Psychosocial resources, M (SD)				
Socioemotional support, preplacement	3.30 (0.48)	3.34 (0.46)	3.36 (0.41)	3.37 (0.40)
Mastery, preplacement	2.80 (0.52)	2.83 (0.52)	2.92 (0.51)	2.89 (0.53)
Psychological outcomes, M (SD)				
Depression, preplacement	1.93 (0.71)	1.92 (0.71)	1.90 (0.69)	1.84 (0.66)
Guilt, preplacement	1.65 (0.59)	1.63 (0.59)	1.67 (0.59)	1.63 (0.57)
Anger, preplacement	1.64 (0.59)	1.65 (0.62)	1.59 (0.51)	1.51 (0.48)
Anxiety, preplacement	1.85 (0.78)	1.84 (0.79)	1.82 (0.75)	1.69 (0.67)
Context of care				
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Note: SD = standard deviation.

panel (i.e., preplacement plus two postplacement waves): n = 146; 3-wave postplacement panel (preplacement plus three postplacement waves): n =109; 4-wave postplacement panel (preplacement plus four postplacement waves): n = 75; and 5-wave postplacement panel (preplacement plus five postplacement waves): n = 38. Figure 1 provides detailed information on study flow for each postplacement panel. Reasons caregivers and their care recipients were excluded from the postplacement analyses were because the care recipient died or the caregiver/care recipient was lost to follow-up during the course of the CSCS. In particular, a considerable proportion of care recipients died during the follow-up period of each postplacement panel (38.2% in the 2-wave panel; 42.1% in the 3-wave panel; 46.4% in the 4-wave panel; and 51.5% in the 5-wave panel; see Figure 1). As the CSCS continued to administer annual interviews to caregivers following bereavement, we considered including these caregivers in the subsequent analyses. However, the considerable differences between these individuals and others caregivers demonstrated in the parent CSCS analyses and other longitudinal research (Aneshensel et al., 1995; Schulz et al., 2004) led to the decision to exclude these respondents.

Measures

CSCS researchers administered the following measures to respondents who were providing care to relatives in the community (i.e., at home) as well as following a relative's NH placement. For specific item information, see Aneshensel and colleagues (1995) or Pearlin, Mullan, Semple, and Skaff (1990). We present reliability estimates from the baseline community sample.

Primary Subjective Stress.—A 3-item measure assessed caregivers' feelings of emotional exhaustion

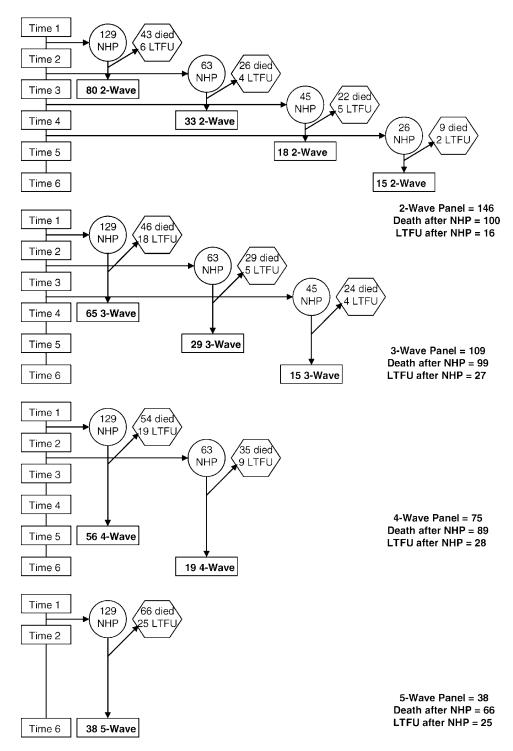


Figure 1. Construction of the postplacement cohorts. NHP = nursing home placement; LTFU = loss to follow-up.

and fatigue due to informal care provision (role overload; baseline $\alpha = .78$). Role overload was rated on a Likert scale, with item responses ranging from not at all (1) to completely (4).

Intrapsychic Strain.—A 2-item measure assessed loss of self ("How much have you lost: a sense of who you are; an important part of yourself?";

r = .60). Item responses ranged from not at all (1) to very much (4).

Psychosocial Resources.—A 5-item socioemotional support scale assessed the amount of emotional connection caregivers felt toward their social networks (baseline $\alpha = .84$). Mastery was measured on a 7-item scale that ascertained caregivers' feelings of

control over important circumstances and events (baseline $\alpha = .75$). Both measures had item responses ranging from strongly disagree (1) to strongly agree (4).

Psychological Outcomes. —A 7-item scale derived from the Hopkins Symptoms Checklist measured depression (Derogatis, Lipman, Covi, & Rickels, 1971). Caregivers were asked how often symptoms had occurred in the past week, with responses ranging from no days (1) to 5 or more days (4; baseline $\alpha = .86$). Researchers used a 5-item scale to assess the belief that one had not done all he or she could have for the care recipient (i.e., guilt; baseline $\alpha = .68$), and the anger and anxiety measures each derived from the Hopkins Symptoms Checklist as 4-item scales (baseline $\alpha = .81$ and .79, respectively; Derogatis et al., 1971). Psychological outcomes had item responses ranging from not at all (1) to very much (4).

Analysis

Panel Comparisons.—The first objective of the longitudinal analysis was to compare differences in the 2-wave, 3-wave, 4-wave, and 5-wave postplacement panels. Utilizing a series of bivariate analyses (e.g., analyses of variance and chi-square tests), we compared each panel on the following characteristics: preplacement primary subjective stressors, intrapsychic strain, psychosocial resources, psychological outcomes, and sociodemographic indicators. These initial analyses provided some insight as to whether the composition of each postplacement panel varied.

Intraindividual Trajectories of Change.—For each outcome variable, we empirically "fit" a longitudinal trajectory to ascertain patterns of change following institutionalization in the 2- through 5wave postplacement interval panels. To achieve this objective, we applied the first stage of a growth curve model to each outcome. Growth curve modeling (also know as *hierarchical* or *multilevel modeling*) consists of two empirical levels: a within-subjects model that examines patterns of intraindividual change (akin to a random effects model, in which each individual's intercept and rate of change/slope is estimated) and a between-subjects model that examines potential predictors/correlates of intraindividual change (or the *fixed effects model*; see Raudenbush & Bryk, 2002; Rogosa, 1996). As the focus of this study was to discern patterns of caregiver adaptation over various lengths of time postplacement, the withinsubjects/random effects model was the focus of subsequent analyses. The within-subjects model examined each individual's growth as a function of time. We achieved this via empirical fit of model parameters that described change over time in each individual. LISREL (Jöreskog & Sörbom, 1993) provided a range of statistics, including variance estimates of parameters, estimates of mean level change, and multiple goodness-of-fit indices to help us ascertain how individuals changed on a given outcome over time.

Although the inclusion of multiple waves of data allowed for curvilinear intraindividual trajectories, inclusion of these parameters in subsequent models did not add substantially to the description of change in postplacement outcomes. For these reasons, and in order to enhance comparisons between the various longitudinal panels, we considered only linear change. This led to the analysis of two parameters for each outcome in the postplacement panels: initial status and rate of change (i.e., slope).

Results

Panel Comparisons

Table 1 provides the results of the bivariate comparisons (e.g., chi-square analyses and one-way analyses of variance) between the 2-, 3-, 4-, and 5-wave postplacement panels. The results showed no significant (p < .05) variations in the longitudinal composition of dementia caregiving subsamples following institutionalization.

Intraindividual Trajectories

Table 2 provides parameter estimates for each postplacement panel. Several indicators demonstrated significant mean change over the 2-wave postplacement interval. Role overload appeared to decrease considerably following placement ($M_{\rm rate~of~change} = -.25, p < .05$). Anxiety and anger also demonstrated notable decreases following care recipients' NH admission ($M_{\rm rate~of~change} = -.10, p < .05$; $M_{\rm rate~of~change} = -.12, p < .05$). Depression also decreased slightly ($M_{\rm rate~of~change} = -.07, p < .05$). Average change across these variables was generally uniform, as there was no significant intraindividual variance in the rate of change parameters.

The 3-wave postplacement panel demonstrated similar patterns of change and variance as the 2-wave postplacement panel. Role overload appeared to demonstrate the most significant mean change over time ($M_{\rm rate~of~change} = -.10$, p < .05). Caregivers also indicated a notable decrease in anxiety during the 3-wave postplacement interview ($M_{\rm rate~of~change} = -.12$, p < .01). Other rate of change parameters suggested caregivers indicated slight decreases in loss of self ($M_{\rm rate~of~change} = -.04$, p < .05), depression ($M_{\rm rate~of~change} = -.09$, p < .01), and anger ($M_{\rm rate~of~change} = -.09$, p < .01). As in the 2-wave postplacement panel, trajectories of change were uniform, with no significant intraindividual variance found.

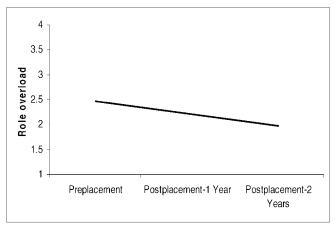
Patterns of mean change in the 4-wave postplacement panel were similar to those in the 3-wave post-

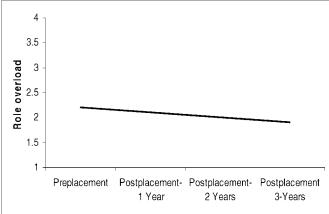
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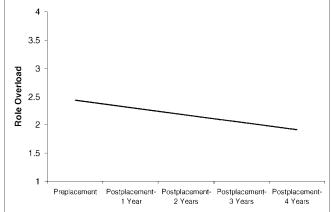
Table 2. Growth Curve Parameters: Intraindividual Variance and Mean Estimates

	2-Wave Postplacement (N	ment $(N = 242)$	3-Wave Postplacemen	placement	4-Wave Postplacement	placement	5-Wave Postplacemen	placement
Parameter	Variance (SE) (Random Effect)	M (SE)	Variance (SE) (Random Effect)	M (SE)	Variance (SE) (Random Effect)	M (SE)	Variance (SE) (Random Effect)	M (SE)
Primary subjective stressors Role overload: Initial status Role overload: Rate of change	.35 (.11)* .08 (.05)	2.47 (.08)*** -0.25 (.04)**	.30 (.09)*	2.20 (.07)*** -0.10 (.03)*	.42 (.10)* .02 (.01)	2.43 (.08)*** -0.13 (.02)**	.41 (.09)*	2.27 (.09)*** -0.06 (.02)*
Intrapsychic strain Loss of self: Initial status Loss of self: Rate of change	.24 (.09)* .01 (.05)	1.88 (.06)*** -0.04 (.03)	.25 (.06)* 01 (.01)	1.82 (.06)*** -0.04 (.02)*	.31 (.07)* .00 (.01)	1.82 (.07)*** -0.05 (.02)*	.23 (.06)*	1.72 (.07)*** -0.03 (.01)*
Psychosocial resources Socioemotional support: Initial status Socioemotional support: Rate of change Mastery: Initial status Mastery: Rate of change	.13 (.03)** .01 (.01) .13 (.03)* .01 (.01)	3.29 (.03)*** -0.01 (.02) 3.29 (.04)*** -0.01 (.02)	.13 (.03)* .00 (.00) .16 (.02)**	3.33 (.04)*** 0.01 (.01) 2.81 (.04)*** 0.01 (.01)	.12 (.02)** .00 (.00)* .16 (.03)** .00 (.00)	3.36 (.03)*** 0.00 (.01) 2.81 (.04)*** 0.01 (.01)	.09 (.02)* .00 (.00)* .18 (.04)** .00 (.00)	3.41 (.04)*** -0.01 (.01) 2.83 (.05)*** 0.02 (.01)*
Psychological outcomes		4 5 5 6 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7	***************************************			444 (10)	4,000	
Depression: Initial status Depression: Rate of change	.31 (.0/)*** .04 (.03)	$1.91 (.06)^{***}$ $-0.07 (.03)^{*}$.33 (.03)***	1.89 (.06)*** $-0.09 (.02)$ **	.40 (.07) .00 (.00)	1.94 (.07)*** $-0.07 (.01)$ **	.01 (.00)*	$1.85 (.08)^{***}$ $-0.05 (.02)^{*}$
Guilt: Initial status	.17 (.05)*		.24 (.05)**		_		.22 (.05)*	
Guilt: Rate of change Anxiety: Initial status	02 (.03) .41 (.09)*	-0.01 (.02) $1.87 (.07)***$.01 (.01)* .41 (.08)**	-0.02 (.02) $1.82 (.07)***$.01 (.00)* .46 (.08)**	-0.03 (.01)* $1.84 (.07)$ ***	.00 (.00)* .36 (.08)*	0.00 (.01) $1.72 (.08)***$
Anxiety: Rate of change	.07 (.04)				_		(00.) 00.	
Anger: Initial status Anger: Rate of change	.16 (.05)* 01 (.02)	1.63 (.04)*** -0.12 (.02)**	.19 (.04)** .01 (.01)	$1.55 (.05)^{***} -0.09 (.02)^{**}$.21 (.04)* .00 (.00)	1.55 (.05)*** $-0.06 (.01)*$.21 (.05)* .00 (.00)*	1.50 (.06)*** $-0.04 (.01)$ *
Motor. CH = standard error								

Notes: SE = standard error."p < .05; **p < .01; ***p < .001.







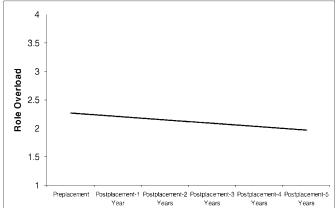


Figure 2. Mean trajectory of change in postplacement role overload.

placement panel. Role overload and anxiety continued to demonstrate a significant decrease ($M_{\rm rate~of~change} = -.13$, p < .01; $M_{\rm rate~of~change} = -.10$, p < .01; see Figures 2 and 3, respectively). Loss of self ($M_{\rm rate~of~change} = -.05$, p < .05), depression ($M_{\rm rate~of~change} = -.07$, p < .05), guilt ($M_{\rm rate~of~change} = -.06$, p < .05) and anger ($M_{\rm rate~of~change} = -.06$, p < .05) showed a slight decrease. Unlike the earlier panels, however, significant intraindividual variance was present in trajectories of socioemotional support and guilt, suggesting that rate of change began to vary for these indicators as greater time elapsed from the institutionalization event.

By the 5-wave postplacement panel, there were slight, significant decreases on role overload ($M_{\rm rate}$ of change = -.06, p < .05), loss of self ($M_{\rm rate}$ of change = -.03, p < .05), depression ($M_{\rm rate}$ of change = -.05, p < .05), anxiety ($M_{\rm rate}$ of change = -.07, p < .05), and anger ($M_{\rm rate}$ of change = -.04, p < .05) and a slight increase in mastery ($M_{\rm rate}$ of change = .02, p < .05). Another trend in the 5-wave postplacement panel was increased variance across trajectories; socioemotional support, depression, guilt, and anger all demonstrated significant intraindividual variance on rate of change. This suggests that a number of

caregivers indicated diverse patterns of change within the 5-wave postplacement panel.

Overall, two variables did exhibit significant and notable mean change across the postplacement panels: role overload and anxiety (see Figure 2 for graphical displays of mean change for these variables). Other indicators demonstrated slight decreases across the postplacement analyses (e.g., loss of self, depression, anger), although the clinical relevance of this change is arguable. Psychosocial resources such as socioemotional support did not exhibit any mean change. There was also evidence of significant intraindividual variance in the long-term postplacement panels (i.e., 4- and 5-wave panels), suggesting diverse patterns of change for select variables as time since institutionalization increased.

Discussion

Utilizing unique data with up to 4 years of postplacement information, the current study sought to describe how trajectories of stress, resources, and well-being changed after NH placement for dementia caregivers. Following dementia caregivers across the NH transition indicated significant, notable de-

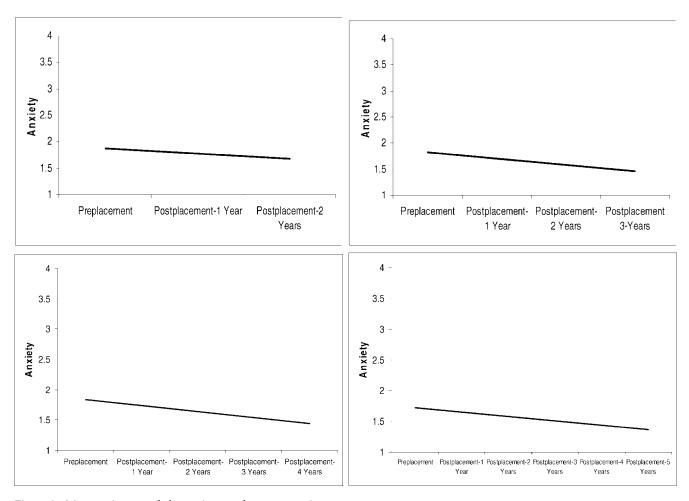


Figure 3. Mean trajectory of change in postplacement anxiety.

creases in role overload and anxiety. For most other indicators there were slight decreases following institutionalization. Overall, as Table 2 suggests, there was little change in most stress process variables, with average trajectories clustering toward more positive adaptation (i.e., lower stress, higher perceptions of psychosocial resources) throughout the longitudinal analysis.

The extensive longitudinal data available revealed several important insights. Average change was most likely to occur in stress process variables over shorter postplacement intervals, with caregivers on average indicating decreases in emotional distress, negative mental health, and similar indicators. These shortterm changes imply that many caregivers experience at least initial relief after institutionalization. For dementia caregivers in longer term panels (i.e., 4 or 5 years postplacement), such decreases appeared less striking. It is possible that placement, with its reprieve from the demands and challenges of athome care, results in a sense of immediate relief for family caregivers. As suggested in other longitudinal dementia caregiving research, the overwhelming nature of care demands coupled with the potentially devastating, firsthand view of the personal deterioration of the relative suffering from dementia may lead to a sense of relief for some caregivers once such an experience has ended (e.g., Aneshensel et al., 1995; Schulz et al., 2003). Conversely, those caregivers in the longer postplacement panels may have been more likely to indicate stability or a less pronounced decrease in emotional stress and negative mental health (due perhaps to a range of factors, such as continued involvement via visits to the relative in the NH, stress related to interactions with facility staff, or other dimensions of the long-term care environment).

A distinct impression that emerges from the longitudinal results is the minimal changes in many stress outcomes over time and across the institutionalization transition. Whereas prior hypotheses of longitudinal adaptation have suggested that with continuing care provision families are more likely to experience distress (i.e., wear and tear; see Townsend et al., 1989), the findings here and from other studies emphasize that caregivers experience stability or even decreases in stress (e.g., Alspaugh, Stephens, Townsend, Zarit, & Greene, 1999; Gaugler, Kane, Kane, & Newcomer, 2005; Pot et al., 1997). Such trends imply an adaptation effect, whereby dementia

caregivers build resilience and coping strategies to manage the occurrence of care demands and other stressors (such as NH placement) over time. Such adaptation was apparent in the mean trajectories. However, it is important to note that there was significant intraindividual variability in several outcomes in the longer term panels (e.g., the 4- and 5wave postplacement panels), suggesting that there are multiple patterns of adaptation as time since NH admission increases. It is possible that during the early years after institutionalization most caregivers are experiencing relief from stressful at-home care responsibilities, thus explaining the uniform patterns of change in the shorter term postplacement panels. As time passes and caregivers become more familiar with and engaged in their post-NH admission roles, other opportunities for distress or, alternatively, psychosocial support emerge. This may explain diverging trajectories among caregivers providing care to relatives who have resided in a NH setting for 3 years or more.

Studies examining the effects of NH placement on caregiver stress, depression, or similar outcomes have often not made distinctions in trajectories and outcomes. Specifically, the overwhelming majority of clinical interventions focus on alleviating caregiver stress and depression among at-home caregivers (e.g., Pinquart & Sörensen, 2006; Schulz et al., 2002; Sörensen, Pinquart, Habil, & Duberstein, 2002). If these various intervention efforts consider institutionalization, they often conceptualize it as an outcome to be prevented or delayed. Those efforts that do focus on family involvement following placement often do not target caregivers at risk for burden or depression. Instead, the few postplacement interventions that have involved family caregivers have tended to focus on building positive family-staff relationships and have not considered how the caregiving situation prior to placement may influence family integration or adaptation immediately following the institutionalization transition (e.g., Gaugler, 2005; Gaugler, Anderson, & Holmes, 2005). The continuity of distress and psychosocial support across institutionalization found in these analyses implies the need for prognostic tools that incorporate preplacement data when identifying families most at risk for negative outcomes following NH admission.

Although the findings suggest an adaptation effect, these results could also indicate a lack of sensitivity in the measures used. Almost all studies of caregiving adaptation following NH placement compare preplacement measures of stress (which are usually designed to assess distress in community care situations) to identical postplacement measures. Although such designs allow for empirical comparisons across the institutionalization transition, these approaches assume that the stress caregivers experience following NH placement is a continuation of stressors encountered in at-home care situations. As

studies of family involvement in residential longterm care emphasize, family members' roles in NHs or similar residential environments may be qualitatively different as personal care responsibilities are largely relinquished to formal care staff and involvement on the part of family members is often in the context of a triad that includes the resident, the family caregiver, and formal care staff (Gaugler, 2005). In these circumstances, family involvement after placement may involve limited hands-on care and the emergence of supervision of and communication with staff (Maas et al., 2004). Following institutionalization, caregiver stress may not be fully captured via comparisons of stress before and after placement; instead, measuring it may require the use of more complex conceptual approaches that consider family-resident-staff interactions along with facility-level characteristics. Example measures could include family perceptions of the difficulty of the placement transition, family assessments of care staff and their ability to meet the needs of institutionalized relatives, or modified versions of traditional measures of stress to incorporate situations or experiences that are of direct relevance to family members caring for relatives in residential care (e.g., incorporation of items related to relationships with staff). Although prior research has incorporated elements of such measures (e.g., see Maas et al., 2004), subsequent efforts that conduct more formal psychometric tests of newly generated measures of family adaptation to NH admission may help to fill this notable gap in the literature.

There are several limitations that are important to address. First, this study examined trajectories of change in caregiver reports of stress, psychosocial resources, and well-being, but, as alluded to previously, these measures may not be sensitive to the stressors that emerge following institutionalization (e.g., supervision of and/or interactions with staff). For this reason, the results may underestimate the challenges of institutionalization for dementia caregivers. Second, the available statistical power to meaningfully model potential predictors was limited, given the number of caregivers available in the longterm follow-up panels (e.g., 4 and 5 years postplacement). Larger samples may have also offered greater intraindividual variance in the shorter term panels, suggesting the presence of factors that could have explained changes in stress, psychosocial resources, or well-being across the placement transition. For example, incorporating contextual characteristics such as caregiver gender or kin relationship to the institutionalized relative could have provided insight into how certain subgroups of dementia caregivers adapt to NH admission. Other limitations of the sample include the age of the data set (see above). The emergence of other modes of residential longterm care in the past 15 years is important to note when examining the caregiving career; the current data set did not consider these. The availability of medications and their utilization were not well-documented in the CSCS (particularly post-NH admission), and such factors may have had an influence on dementia-related symptoms as well as caregivers' reports of distress. Moreover, the sample was one of convenience and is not generalizable to the population of dementia caregivers in the United States.

From a clinical standpoint, these findings and others (Schulz et al., 2003) suggest that the longterm nature of dementia caregiving requires longterm support strategies that are oriented around the various transitions that emerge in the context of the caregiving career, whether they be onset (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Gaugler, Zarit, & Pearlin, 2003b; Pot, Zarit, Twisk, & Townsend, 2005); the provision of intensive, athome care (Mittelman, Roth, Coon, & Haley, 2004; Mittelman, Roth, Haley, & Zarit, 2004; Schulz et al., 2004); community-based service utilization (Gaugler & Zarit, 2001); institutionalization; or bereavement (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Schulz et al., 2001). Descriptive analysis of the long-term implications of key transitions in the dementia caregiving career is the first step in developing more complex predictive studies. Such foundational efforts could then provide guidance in the implementation of interventions that assist caregiving families navigate the various transitions that occur during dementia.

Another important practice implication for these results is the insight they provide regarding the timing of interventions after placement. Existing interventions for families following NH placement generally focus on family members with residents of varying durations of stay and attempt to facilitate family-staff communication or partnerships (Gaugler, Kane, et al., 2005). Similar to community-based interventions for dementia caregivers, they rarely consider issues of timing; it may be that providing family-level support with an emphasis on family-staff care partnerships or education during and immediately following a relative's entry is most beneficial (e.g., Maas et al., 2004; Pillemer et al., 2003; for an example program directed at NH discharge, see Newcomer, Kang, & Graham, 2006). Long-term support could then focus on more ad hoc types of guidance (e.g., monthly meetings between family members and care staff to discuss care roles and personal issues of importance to the resident and family). In this manner, intensive support targeted to those time periods when families may be most at risk for negative outcomes could maximize the abilities of families to continue to remain effectively involved in the life of the resident well after the transition to NH care.

References

Alspaugh, M. E. L., Stephens, M. A. P., Townsend, A. L., Zarit, S. H., & Greene, R. (1999). Longitudinal patterns of risk for depression in

- dementia caregivers: Objective and subjective primary stress as predictors. *Psychology and Aging*, 14, 34-43.
- Aneshensel, C. S., Botticello, A. L., & Yamamoto-Mitani, N. (2004). When caregiving ends: The course of depressive symptoms after bereavement. *Journal of Health and Social Behavior*, 45, 422–440.
- Aneshensel, C. S., Pearlin, L. I., Levy-Storms, L., & Schuler, R. H. (2000). The transition from home to nursing home mortality among people with dementia. *Journal of Gerontology: Social Sciences*, 55B, S152– S162.
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). Profiles in caregiving: The unexpected career. San Diego, CA: Academic Press.
- Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, 43, 230–241.
- Derogatis, L. R., Lipman, R. S., Covi, L., & Rickels, K. (1971).

 Neurotic symptom dimensions. Archives of General Psychiatry, 24, 454–464.
- Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention. *Neurology*, 51(Suppl. 1), S53–S60.
- Fisher, L., & Lieberman, M. A. (1999). A longitudinal study of predictors of nursing home placement for patients with dementia: The contribution of family characteristics. *The Gerontologist*, 39, 677–686.
- Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, 9, 105–118.
- Gaugler, J. E., Anderson, K. A., & Holmes, H. H. (2005). Family-based intervention in residential long-term care. Marriage and Family Review, 37, 45–62
- Gaugler, J. E., Anderson, K. A., Zarit, S. H., & Pearlin, L. I. (2004). Family involvement in the nursing home: Effects on stress and well-being. Aging & Mental Health, 8, 65–75.
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). The longitudinal influence of early behavior problems in the dementia caregiving career. *Psychology and Aging*, 20, 100–116.
- Gaugler, J. E., & Zarit, S. H. (2001). The effectiveness of adult day services for disabled older people. *Journal of Aging and Social Policy*, 12, 23–47
- Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003a). Family involvement following institutionalization: Modeling nursing home visits over time. *International Journal of Aging and Human Development*, 57, 91–117
- Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003b). The onset of dementia caregiving and its longitudinal implications. *Psychology and Aging*, 18, 171–180
- Jöreskog, K. G., & Sörbom, D. (1993). LISREL 8: Structural equation modeling with the SIMPLIS command language. Chicago, IL: Scientific Software International.
- Maas, M. L., Reed, D., Park, M., Specht, J. P., Schutte D., Kelley, L. S., et al. (2004). Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nursing Research*, 53, 76–96
- Mitchell, S. L., Kiely, D. K., Hamel, M. B., Park, P. S., Morris, J. N., & Fries, B. E. (2004). Estimating prognosis for nursing home residents with advanced dementia. *Journal of the American Medical Association*, 291, 2734–2740.
- Mittelman, M. S., Roth, D. L., Coon, D. W., & Haley, W. E. (2004). Sustained benefit of supportive intervention for depressive symptoms in Alzheimer's caregivers. *American Journal of Psychiatry*, 161, 850– 856.
- Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *Journal of Gerontology: Psychological Sciences*, 59B, P27–P34
- Newcomer, R., Kang, T., & Graham, C. (2006). Outcomes in a nursing home transition case-management program targeting new admissions. *The Gerontologist*, 46, 385–390.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594.
- Pillemer, K., Suitor, J. J., Henderson, C. R., Meador, R., Schultz, L., Robison, J., et al. (2003). A cooperative communication intervention for nursing home staff and family members of residents. *The Gerontologist*, 43(Special Issue II), 96–106.
- Pinquart, M., & Sörenson, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are effects? *International Psychogeriatrics*, 18, 577–595.
- Pot, A. M., Deeg, D. J. H., & van Dyck, R. (1997). Psychological well-being of informal caregivers of elderly people with dementia. *Aging & Mental Health*, 1, 261–268.
- Pot, A. M., Zarit, S. H., Twisk, J. W., & Townsend, A. L. (2005). Transitions

- in caregivers' use of paid home help: Associations with stress appraisals and well-being. *Psychology and Aging*, 20, 211–219.
- Raudenbush, S. W., & Bryk, A. S. (2002). Hierarchical linear models: Application and data analysis methods (2nd ed.). Thousand Oaks, CA: Sage.
- Rogosa, D. R. (1996). Myths and methods: Myths about longitudinal research plus supplemental questions. In J. M. Gottman (Ed.), *The analysis of change* (pp. 3–66). Mahwah, NJ: Erlbaum.
- Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., et al. (2001). Involvement in caregiving and adjustment to death of a spouse: Findings from the Caregiver Health Effects Study. *Journal of the American Medical Association*, 285, 3123–3129.
- Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, 292, 961–967.
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., et al. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. New England Journal of Medicine, 349, 1936–1942.
- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., et al. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist*, 42, 589–602.

- Sörensen, S., Pinquart, M., Habil, X., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42, 356–372.
- Townsend, A., Noelker, L., Deimling, G., & Bass, D. (1989). Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychology and Aging*, 4, 393–401.
- Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., et al. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *Journal of the American Medical Associa*tion, 287, 2090–2097.
- Yamamoto-Mitani, N., Aneshensel, C. S., & Levy-Storms, L. (2002).
 Patterns of family visiting with institutionalized elders: The case of dementia. *Journal of Gerontology: Social Sciences*, 57, S234–S246.
- Zarit, S. H., & Whitlatch, C. J. (1992). Institutional placement: Phases of transition. *The Gerontologist*, 32, 665–672.

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