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What is This?
Caring for Grandparents With Alzheimer’s Disease: Help From the “Forgotten” Generation

Sharon Boland Hamill¹

Abstract
This study examined adolescent grandchildren’s contributions to caregiving for grandparents with Alzheimer’s disease. It was predicted that grandchilden would provide more care when parents experienced greater burden, and when adolescents had higher quality relationships with parents and grandparents. It was also hypothesized that these factors would predict higher levels of social commitment and more positive attitudes toward the provision of long-term care. Twenty-nine adolescents and their parents participated in the telephone interview study. Adolescents rated the amount of care they provided to grandparents, relationship quality with grandparents and parents, social responsibility, and attitudes toward the provision of long-term care. Parents reported levels of caregiver burden. Results indicated that grandchildren provided more help when parents provided more care and when grandchildren had greater affection for grandparents. Adolescent grandchildren exhibited lower levels of social responsibility and more negative attitudes toward the provision of long-term care when fathers experienced higher subjective burden.

Keywords
young caregivers, auxiliary caregivers, Alzheimer’s disease, social responsibility

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Each day, millions of families in the United States face the challenges of providing care to dependent older adult family members. At present, 43.5 million caregivers aged 18 years and older in the United States are currently providing care to individuals 50 years of age or older (National Alliance for Caregiving and American Association of Retired Persons [AARP], 2009). Almost 15 million caregivers are providing assistance to the 5.4 million older adults with Alzheimer’s disease (AD; Alzheimer’s Association, 2011). Approximately 60% of caregivers provide assistance with the basic tasks of daily life such as toileting, bathing, and feeding; spouses and adult children are the family members most likely to fulfill this caregiving role (National Alliance for Caregiving and AARP, 2009). However, there is increasing evidence that grandchildren are also called on to provide care. A study on a random sample of U.S. households revealed that there are approximately 1.3 to 1.4 million child caregivers younger than 18 years in the United States. Of these, 31% provided assistance to a grandparent, 18% of whom were diagnosed with AD (National Alliance for Caregiving and the United Hospital Fund, 2005). The number of families enlisting grandchildren as caregivers is likely to increase given that AD cases are expected to double by 2030 and triple by 2050, leaving an estimated 11 to 16 million people with the disease and their family members faced with providing care (Alzheimer’s Association, 2011). Whereas research has revealed quite a bit about the contributions of adult children providing care for their parents who are afflicted with AD, far less is known about the experiences of adolescent grandchildren. In fact, the United States lags about 10 years behind the UK and Australia in its understanding of young caregivers (Becker, 2007). However, a growing literature has begun to consider the contributions of the “forgotten generation” (Howard & Singleton, 2001), those children and adolescents whose contributions to informal caregiving may be hidden (Becker, 2007; Fruhauf & Orel, 2008; Siskowski, 2006). Family systems theory provides a useful theoretical base for understanding the role that these grandchildren play in families of older adults with AD.

Family systems theorists view families as systems of individually developing members who are connected through relationship bonds (von Eye & Kreppner, 1989; Whitchurch & Constantine, 1993). Typical day-to-day functioning of the family entails constant adaptation to the changing needs of its members, with families striving to keep stress at a minimum. When there are drastic changes in a family member, such as the declining health of a grandparent, the effects reverberate throughout the family system to go beyond individual dyads (e.g., grandparent–parent) to affect other family relationships (e.g., parent–adolescent grandchild). For example, when grandparents...
experience declines in autonomy and control due to AD, parents are likely to assume the role of primary or secondary caregivers in which they provide hands-on assistance and are responsible for making decisions regarding the grandparent’s care. In response to changing family needs, adolescent grandchildren may be asked to take on more responsibilities at home as parents turn their attention to grandparents’ care (Goodnow & Lawrence, 2001). Typically, these young people serve as auxiliary caregivers to their grandparents, providing hands-on care, but having no decision-making capabilities (Dilworth-Anderson, Williams, & Cooper, 1999; Fruhauf & Orel, 2008). However, grandchildren may not be ready for the caregiver role (Dellmann-Jenkins, Blankemeyer, & Pinkard, 2001).

Whereas parents are at a developmental point where they can use advanced cognitive functions and resources to deal with caregiving stressors in order to maintain equilibrium, adolescent grandchildren may not yet have these resources available because of characteristic developmental changes they are undergoing themselves. Additionally, parents may have difficulty providing the time and attention necessary for positive and supportive family relations with their adolescents when they are consumed with caregiving responsibilities. The result is likely to be increases in family tension and more difficulty finding equilibrium. Yet relatively few studies focus specifically on the impact of caregiving on family members beyond the primary caregiving dyad (Orel & Dupuy, 2002; Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Szinovacz, 2003). The purpose of this exploratory study was to address this gap by exploring the caregiving responsibilities adolescent grandchildren assume when their grandparents are diagnosed with AD. Specifically, it focused on grandchildren’s participation in caregiving activities, current outcomes for adolescent development, and adolescents’ plans to serve as caregivers in the future.

**Young Caregivers**

Research on young caregivers has varied considerably in terms of the age of the caregiver, the relationships they share with recipients of care, and differential diagnoses of care receivers. Examination of the extant literature on grandchildren as caregivers reveals that there is quite a bit of variation in age of the young caregiver. For example, studies have defined young caregivers as young adults aged 18 to 40 years (Dellmann-Jenkins & Brittain, 2003), adolescents aged 14 to 21 years (Celdrán, Triadó, & Villar, 2009), or minor children between 8 and 18 years (National Alliance for Caregiving and the United Hospital Fund, 2005). Yet these time frames pose different issues for
the young caregiver. For those aged 18 to 40 years, caregiving responsibili-
ties are assumed during a time in life when young people are confronting
developmental tasks that will allow them to build foundations for their own
adult lives. Dellmann-Jenkins, Blankemeyer, and Pinkard (2000) character-
ized this time as a “demographically dense” period in which young people
move out of the family home, actively seek a mate, and establish themselves
in a job or career. The researchers found that caregiving resulted in delays in
meeting developmental tasks as young caregivers were less likely to live
independently, had difficulties in establishing or maintaining romantic rela-
tionships, and were reluctant or unable to take advantage of career opportu-

nities. An important point to underscore in these studies is that young
caregivers 21 years and older are considered legal adults in most domains
and may have greater decision-making abilities than those who are younger;
consequently, they may be able to exert greater control over their life circum-
stances. However, caregiving experiences may be considerably different for
younger caregivers.

Research in the United Kingdom, Australia, and the United States suggest
that the average age of “young” caregivers is 12 to 13 years (National Alliance
for Caregiving and the United Hospital Fund, 2005; Noble-Carr, 2002;
Siskowski, 2006). A primary concern when taking on the caregiver role at
such a young age is that these young people are experiencing rapid develop-
ment themselves. Adolescent identity development, pubertal changes, and
shifting dynamics in the relationships with parents make this period of life a
particularly lively one. Incorporating the care of a grandparent on top of these
challenging developmental tasks requires quite a bit of adjustment on the part
of the young person. This task may be made even more difficult given ado-
lescents’ limited cognitive understanding of aging, dependence, and death.
Undergoing these developmental changes while grandparents exhibit increas-
ing need due to disorders such as AD may make adolescents particularly
attuned to both positive and negative parental models of care. This may have
repercussions for family functioning and for future roles, as adolescents are
exploring their values regarding care for others in a context where their par-
ents, and they themselves, are actively fulfilling caregiver roles.

Research reveals that young caregivers help a variety of family members
across a considerable age range, including siblings, parents, grandparents, or
some combination of all three (National Alliance for Caregiving and the
United Hospital Fund, 2005). This conceptualization confounds a number of
variables which makes interpretation of findings difficult. For example, care
for a sibling may involve assistance with activities of daily living (e.g., assis-
tance with toileting) but it is not likely to be psychologically equivalent to the
same care provided to an adult. Psychologically, the care of parents and grandparents often involves more issues of role reversal and a sense of being off-time (Fruhauf, Jarrott, & Allen, 2006). Caregivers may feel that they should be taken care of themselves, given their ages, rather than being placed in the role of taking care of older family members. To more clearly define the activities of young caregivers, analyses should differentiate between the different types of relationships (sibling, parent, grandparent) involved in caregiving situations.

Finally, the research on young caregivers shows that they help family members suffering from a variety of physical and mental disorders. Some studies may include care recipients with chronic illnesses such as Parkinson’s disease, heart conditions, or dementia in a single sample (e.g., Piercy, 2007). Others may focus solely on dementia (e.g., Celdrán et al., 2009; Celdrán, Triadó, & Villar, 2011; Creasey & Jarvis, 1989; Creasey, Myers, Epperson, & Taylor, 1989) and several do not specify the type of illness (e.g., Dellmann-Jenkins & Brittain, 2003; Shifren, 2008). However, failing to distinguish between different types of illness makes it difficult to interpret results. Caregiving takes on different meanings when dealing with an acute versus a chronic condition. Moreover, research shows it is more difficult to care for those with dementia (Bertrand, Fredman, & Saczynski, 2006). AD is an illness that will progress over many years, in some cases, for the entire childhood and adolescence of grandchildren. The chronic behavioral disturbances AD patients exhibit, the high level of care they require, and the extended duration of the caregiver role make it an especially difficult disease for a family to manage and it will touch members throughout the family system (Celdrán et al., 2009, 2011; Creasey et al., 1989; Creasey & Jarvis, 1989). To best understand the young caregiver role in these families, it is critical that studies consider the wider family ecology of caregiving.

The Ecology of Family Caregiving and the Socialization of the Young

Each family providing care does so in a unique environment influenced by past experiences, current challenges, and future goals. This family ecology is critical to understanding the nature of the caregiving experience. For example, some research suggests that young caregivers assist grandparents in response to direct requests from their parents and other relatives to do so (Dellmann-Jenkins & Brittain, 2003). Perhaps the parents are in desperate need of the caregiving support and have no choice but to require adolescents to participate in family caregiving. Alternately, other parents might actively discourage
adolescents from caregiving because they do not want to burden their children. Additionally, quality of existing family relationships is likely to play a role. Research with adult caregivers indicates that positive relationships with older parents is related to more help provided and a sense that help is provided by choice rather than obligation (Cicirelli, 1993; Walker, Pratt, Shin, & Jones, 1989). Research with young caregivers also shows that many provide care out of love for their grandparents (Dellmann-Jenkins & Brittain, 2003). However, it is also likely that closeness to parents may serve as a foundation for grandparent care as adolescents who have close relationships with parents may be more in tune with the stresses and challenges their parents face as caregivers and therefore be more willing to lend a hand to help. The quality of relationships with parents in the family ecology of caregiving has received little attention in research. The fact that good relationships with parents are critical for optimal adolescent development underscores the importance of studying the quality of these relationships in the context of family caregiving.

A specific opportunity for positive adolescent outcomes afforded by family caregiving is the role that it may play in the socialization of prosocial attitudes and behaviors (Beach, 1997). Prosocial attitudes and behaviors increase during adolescence (Eisenberg, Miller, Shell, Mcalley, & Shea, 1991; Greenberger, Josselson, Knerr, & Knerr, 1975), and they appear to be qualitatively different from those displayed previously. During adolescence, “childhood versions of prosocial attitudes and behavior are transformed into those that will more permanently identify the youth and young adult as an individual who does or does not engage in caring behaviors” (Chase-Lansdale, Wakschlag, & Brooks-Gunn, 1995, p. 524). This transformation is most likely due to the identity development that adolescents undergo; adolescents must reconcile physical, cognitive, and social changes to produce a coherent sense of who they are (i.e., identity) and their connection to the world. An outcome of this development is greater concern with the welfare of others and increased emphasis on the future roles and responsibilities that adolescents will have in their adult lives (Collins, Gleason, & Sesma, 1997). This may be manifested in adolescents’ feelings about their responsibilities to help others and their willingness to assist their own parents when the time comes. At present, little is known about the links between caregiving experiences of young caregivers, current levels of commitment to others, and future plans regarding caregiver roles.

The Present Study

The present study was designed to explore the caregiving experiences of youths, aged 21 years and younger, who were providing care to grandparents.
with AD. It focused on the kinds of tasks that grandchildren performed, factors related to the provision of care, and the outcomes of these caregiving experiences. Specifically, it addressed the following research questions: (a) Do grandchildren provide direct help to grandparents with dementia? (b) If so, what kinds of tasks do they perform? Additionally, this study predicted that (a) greater parental caregiving burden and more positive relationships with parents and grandparents would predict higher levels of adolescent caregiving and (b) these factors would predict greater social responsibility among adolescents and more positive attitudes toward the provision of long-term care for older parents in the future.

Method

Participants

Adolescents, mothers, and fathers from 35 families participated in a structured telephone interview study of caregiving families providing assistance to grandparents suffering from AD. For this report, only families in which the adolescent participated were included. Participants were 29 adolescents aged 11 to 21 years (M = 15.88 years, SD = 2.54), 29 mothers aged 30 to 56 years (M = 45.97 years, SD = 6.34), and 24 fathers aged 35 to 67 years (M = 49.04 years, SD = 7.9). There were 8 male adolescents (27.6%) and 21 females (72.4%). All but one of the adolescents lived in the family home. Seven families were Mexican American (24.1%), and the remaining were White (75.9%). Parents were given the choice of completing the interview in English or Spanish. The measures were first professionally translated; bilingual research assistants reviewed the translated measures for accuracy. Three fathers and five mothers completed the interviews in Spanish. Parents had been married an average of 20.58 years (SD = 9.08). The families were predominantly Catholic (37.9%) and Protestant (34.5%), as reported by the mothers.

Measures

Grandparent in need of help. Mothers indicated the grandparent for which the family provided help: maternal grandmother, maternal grandfather, paternal grandmother, paternal grandfather, other older family member, or multiple older family members. They provided information on the grandparent’s age, whether the grandparent had been diagnosed with AD, when he or she received the diagnosis and his or her place of residence.
Parent’s objective level of caregiver burden. Each parent reported the number of hours he or she provided help to the grandparent during the past week.

Parent’s subjective level of caregiver burden. Parents completed the Zarit Burden Interview (Zarit & Zarit, 1987) as a measure of psychological burden in the caregiving relationship. This 22-item measure was designed to reflect the stresses experienced by caregivers of dementia patients. Caregivers indicated how often they have felt a particular way about taking care of their family member by rating the items using a 5-point Likert-type scale (0 = never and 4 = nearly always). Higher scores indicate greater burden. The authors report internal consistency for the scale to be very good, from .88 to .91. Validity of the measure is demonstrated by its significant association with a single global rating of burden and its relationship to scores on the Brief Symptom Inventory (see, Zarit & Zarit, 1987). In the current sample, the mean subjective burden score for mothers was 1.50 (SD = 0.52; range = 0.64-2.64) and 1.18 for fathers (SD = 0.64; range = 0.18-2.18). Reliability was good for both mothers’ and fathers’ scales (.84 and .90, respectively).

Grandchildren’s objective level of caregiving burden. Adolescent grandchildren’s objective level of burden was assessed with adapted versions of the Penning (1998) Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADL) scales. Adolescents were given a list of basic ADLs (e.g., eating and dressing) and IADLs (e.g., shopping and meal preparation). They were asked to think about any help they provided their grandparent during the past week and indicate whether they had helped the grandparent with each specific task or not (yes/no). These tasks were summed to get a count of the total number of tasks for which the participants provided help. Penning (1998) reported reliability coefficients (Cronbach’s alpha) for the original scales of .90 and .89 for ADL and IADL impairments, respectively. In the current study, the total scale, which combined ADL and IADL assistance, had a reliability of .85.

Additionally, adolescents reported whether they had done anything in the past week to help their mother or father so that he or she would be able to provide care to the grandparent (yes/no).

Affectual solidarity for parents and grandparents. Closeness between the adolescents and their parents and grandparents was assessed with the Affectual Solidarity Scale (Roberts & Bengtson, 1993). Adolescents answered four questions reflecting the closeness they felt in their relationships with each of their parents, and their grandparents. Each question was rated using a 6-point Likert-type scale (1 = not at all well and 6 = extremely well). A sample item is “Overall, how well do you and your mother/father/grandparent get along at this point in your life?” Higher scores indicate greater affection for the family.
member (parent or grandparent). In the current study, this scale demonstrated good reliability (Cronbach’s $\alpha$ [for mothers] = .86, $\alpha$ [for fathers] = .91, $\alpha$ [for grandparents] = .77).

**Social commitment.** Social commitment was assessed by a measure developed by Greenberger et al. (1975). According to Greenberger (1984), one aspect of a socially responsible person is a disposition toward social commitment. This includes feelings of community with others and an investment in long-term social goals. In the present study, the Social Commitment subscale of Greenberger et al.’s (1975) Psychosocial Maturity Inventory (Form D, 11th grade version) was used to tap social responsibility. A sample item from this 11-item scale is “It’s not really my problem if my neighbors are in trouble and need help.” Adolescents rated these items using a 4-point Likert-type scale (1 = agree strongly and 4 = disagree strongly). Higher scores indicate greater social commitment (i.e., more socially responsible attitudes). In this sample, the mean item score was 3.12 ($SD = 0.57$; range = 2-4). The reliability of the scale as reported by the authors was .86 (Greenberger et al., 1975). In the present sample, the scale demonstrated good internal consistency ($\alpha = .82$).

**General willingness to provide long-term care.** An adapted version of Klein’s (1992) Attitude Toward the Provision of Long-Term Care Scale was used to assess general attitudes toward the provision of long-term care for older parents. The original scale considered care given to any dependent family member; in the adapted scale, items were reworded to focus attention on older parents and, four items that were irrelevant for elder care were dropped. Participants responded to 22 statements using a 5-point Likert-type scale (1 = strongly agree and 5 = strongly disagree). A sample item is “Providing care to a disabled elderly parent is a basic human responsibility.” Items were recoded and summed such that higher scores indicate more positive attitudes toward the provision of long-term care. This scale demonstrated good internal consistency in a sample of college students ($\alpha = .87$; Hamill, Klein, & Miller, 2002). Klein (1992) provided evidence of strong concurrent and discriminant validity for the original scale. Cronbach’s alpha for the scale in this current sample of adolescents was .63.

**Plans to be a primary caregiver.** A one-item measure was constructed to assess future caregiving intentions with regard to participants’ own parents. Adolescents were asked to imagine that a situation arose in which their parents needed care when they are older and were told to assume that there were options available for their parents’ care (e.g., living with the participant, living with a sibling, living in an assisted living facility). They then indicated whether (a) they would bring their parents into their own home to provide care, (b) serve as the primary caregiver to their parents in their home, (c) serve
as a secondary or auxiliary caregiver to their parents living elsewhere, or (d) not serve as a caregiver to their parents.

Procedure

Participants were recruited through a variety of sources, including the UCSD’s Shiley-Marcos Alzheimer’s Disease Research Center, the Alzheimer’s Association, newspaper announcements, Health fairs, assisted living facilities, and word of mouth. Families were eligible to participate if they were White or Mexican American, had an adolescent in the home, came from a two-parent family, and had a grandparent who was suffering from AD. The grandparent did not have to live with the family.

Once the family contacted the research lab the study was explained and appointments were made to conduct half-hour structured telephone interviews. Mothers, fathers, and adolescents each had separate interviews with the principal investigator or a trained, bilingual research assistant. Prior to the interview date, consent forms and rating scales were mailed to the family home for reference during the interview; participants mailed consent forms back to the researcher and also gave verbal consent prior to beginning the interview. Complete data were obtained from mothers and adolescents from 82.9% of the families who agreed to participate. Once data collection began, multiple attempts (at least three) were made to reach family members who had not yet participated to schedule or reschedule appointments for interviews. Families were paid $15 for participating in the study and were provided with contacts for local resources regarding the care of individuals with AD. On completion of the study, families were sent letters describing general findings.

Results

Bivariate analyses were run among study variables to examine relationships between caregiving indices, adolescent development, and attitudes toward long-term care. Given that multiple comparisons inflate Type I error, a Bonferroni correction was used to keep the family-wise alpha level at .05. Consequently, only associations at the \( p \leq .03 \) level were considered significant.

Who Do Grandchildren Help?

Mothers provided information on the grandparent for whom they provided help. The maternal grandmother (58.6%) and the paternal grandmother (20.7%) were the most common grandparents to receive care; the remainder
were grandfathers (maternal = 10.3%, paternal = 3.4%) or some other older family member (e.g., aunt or uncle, 6.9%; for the sake of clarity, all older family members will be referred to as grandparents). The mean age for the grandparents was 79.29 years (SD = 8.28). All had been diagnosed with AD by a physician or other professional for an average (median) of 3 years (SD = 6.13); the range of time since diagnosis was below 1 year to 32 years. Twenty percent of the grandparents lived with the adolescent’s family, 44.8% lived in their own home, 24.1% lived in a nursing home, and 10.3% lived in some other residence.

### Table 1. Frequencies of Types of Help Provided

<table>
<thead>
<tr>
<th>Instrumental activities of daily living</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping</td>
<td>27.6</td>
</tr>
<tr>
<td>Meal preparation</td>
<td>34.5</td>
</tr>
<tr>
<td>Housework</td>
<td>48.3</td>
</tr>
<tr>
<td>Managing money</td>
<td>13.8</td>
</tr>
<tr>
<td>Using the telephone</td>
<td>27.6</td>
</tr>
<tr>
<td>Getting to places beyond walking distance</td>
<td>31.0</td>
</tr>
<tr>
<td>Taking medications</td>
<td>20.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activities of daily living</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating</td>
<td>44.8</td>
</tr>
<tr>
<td>Dressing</td>
<td>20.7</td>
</tr>
<tr>
<td>Grooming</td>
<td>31.0</td>
</tr>
<tr>
<td>Walking</td>
<td>37.9</td>
</tr>
<tr>
<td>Getting in and out of bed</td>
<td>3.4</td>
</tr>
<tr>
<td>Bathing</td>
<td>3.4</td>
</tr>
<tr>
<td>Toileting</td>
<td>3.4</td>
</tr>
</tbody>
</table>

Note: n = 29.

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**What Kinds of Assistance and How Much Assistance Do They Provide?**

Overall, 65.5% of adolescents reported helping their grandparents with some task of daily living in the previous week. Sixty-two percent of adolescents reported helping grandparents with IADLs. The most common tasks were housework (48.3%) and meal preparation (34.5%). Surprisingly, 20.7% helped the grandparent take medications and 13.8% assisted the grandparent in managing money (see Table 1). Fifty-five percent indicated that they personally assisted their grandparents with ADLs. Almost 45% provided help...
The average number of tasks with which adolescents assisted was 3.48 (SD = 3.39). Results of a Wilcoxon signed ranks test indicated adolescents assisted with more IADLs than ADLs (Z = −2.01, p < .05). Given that the score for the total number of tasks for which they provided assistance was normally distributed and the ADL and IADL subscales exhibited similar relationships with other study variables, the combined score was used in further analyses.

### Parents’ Caregiving Burden as Predictors of Grandchildren’s Help

Grandchildren’s provision of help to grandparents was explored through bivariate correlations among parents’ hours of care providing to grandparents and the number of tasks for which adolescent grandchildren provided help. Mothers and fathers each reported on the number of hours they spent helping the grandparent in the previous week. These estimates were highly skewed so medians are reported: Mothers spent an average of 12.5 hours helping (range = 0-100) whereas fathers reported an average of 2.25 hours of help (range = 0-36). Results indicated that grandchildren assisted with a greater number of activities when their parents provided more hours of help (Spearman’s ρ = .47, p = .011 for mothers and ρ = .49, p = .015 for fathers, respectively). Parents’ subjective experience of burden was not related to grandchildren’s provision of help (see Table 2).

### Table 2. Correlations Between Parental Burden, Quality of Relationships, and Adolescent Outcomes

<table>
<thead>
<tr>
<th></th>
<th>Adolescent ADL/IADL Total</th>
<th>Social Commitment</th>
<th>Attitudes Toward Long-Term Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother caregiving hours</td>
<td>.47*</td>
<td>.04</td>
<td>.00</td>
</tr>
<tr>
<td>Father caregiving hours</td>
<td>.49*</td>
<td>−.39†</td>
<td>−.09</td>
</tr>
<tr>
<td>Mother burden</td>
<td>−.03</td>
<td>−.14</td>
<td>−.37†</td>
</tr>
<tr>
<td>Father burden</td>
<td>.12</td>
<td>−.62***</td>
<td>−.47*</td>
</tr>
<tr>
<td>Affection for mother</td>
<td>.06</td>
<td>−.15</td>
<td>.03</td>
</tr>
<tr>
<td>Affection for father</td>
<td>−.15</td>
<td>−.08</td>
<td>.22</td>
</tr>
<tr>
<td>Affection for grandparent</td>
<td>.44*</td>
<td>−.05</td>
<td>.34†</td>
</tr>
</tbody>
</table>

Note: ADL = activities of daily living; IADL = instrumental activities of daily living. n = 29 for mother/adolescent variables. n = 24 for father/adolescent variables.

a. Spearman’s rho.

† p < .10, * p < .03, ** p < .01, ***p < .001 (all two-tailed tests).
**Relationship Quality as Predictors of Grandchildren’s Help**

Adolescents’ levels of affection for mothers ($M = 4.88, SD = 0.84; \text{range} = 3.25-6.0$) and fathers ($M = 4.47, SD = 1.11; \text{range} = 1.5-6.0$) were positive, however, levels of affection in their relationships with grandparents were neutral ($M = 3.56, SD = 1.16; \text{range} = 1.25-5.75$). Affection for parents was not related to grandchild help, however, grandchildren who had greater affection for their grandparents provided more help ($r = .44, p = .017$; see Table 2).

**Caregiving and Adolescents’ Sense of Social Commitment**

It was predicted that parents’ caregiving responsibilities and adolescent provision of help would be related to a greater sense of social responsibility in adolescent grandchildren. The mean level of social responsibility in this sample was fairly high ($M = 3.12, SD = 0.57$ on a 4-point scale). Results of bivariate analyses revealed that adolescents reported a lower level of social responsibility when their fathers experienced greater subjective burden in their caregiving roles ($r = −.62, p = .001$). There was a trend for fathers’ hours of help to contribute to lower levels of social responsibility, as well ($r = −.39, p = .058$). No other significant relationships were found.

**Predicting Attitudes Toward the Provision of Long-Term Care**

This study also examined predictors of adolescents’ general attitudes toward the provision of long-term care for older parents. Adolescent ratings revealed generally neutral levels of commitment to long-term care ($M = 3.52, SD = 0.36; \text{range} = 2.68-4.23$ on a 5-point scale). The affection adolescents felt for parents and grandparents, the help parents and adolescents provided to grandparents, and adolescents’ sense of social responsibility were explored as predictors of adolescents’ general attitude toward the provision of long-term care for older parents. Whereas adolescents had more positive attitudes toward long-term care when they helped with more tasks ($r = .44, p = .017$), they had more negative attitudes when their fathers experienced greater caregiver burden ($r = −.47, p = .019$; there was a trend in the same direction for mothers, $r = −.37, p = .051$). No other relationships were significant.

**Plans to Serve as Caregiver to Parents in the Future**

Finally, participants indicated their intentions for providing future care to their own parents. Results indicated that all adolescents planned on providing
care in the future. The majority (59.3%) intended to serve as primary caregivers and provide care in their own homes. An additional 22.2% intend to serve as primary caregivers and 18.5% as secondary or auxiliary caregivers to parents living elsewhere.

Discussion

The primary goal of this study was to explore the caregiving experiences of adolescents whose grandparents were diagnosed with AD. In particular, it considered the kinds of direct help provided to grandparents by grandchildren, and how the ecology of living in a caregiving family was related to adolescents’ participation in caregiving and personal development. Results indicated that most grandchildren did help and were more likely to do so when parents were providing more hours of care and when they had more affectionate relationships with their grandparents. Caregiving also demonstrated relationships with indices of adolescent development. In particular, fathers’ experience of caregiving burden was related to lower levels of adolescent social responsibility and more negative adolescent attitudes toward the provision of long-term care to older parents. These findings provide some insights into the socialization processes adolescents undergo when families take on caregiving roles.

Grandchildren as Auxiliary Caregivers

This study highlights the auxiliary role that adolescent grandchildren play in family caregiving. Whereas early research on caregiving tended to ignore the contributions of adolescent grandchildren (Howard & Singleton, 2001) more recent studies are including them among the constellation of caregivers in the family system (e.g., Celdrán et al., 2011). This study supports this practice. Grandchildren provided direct help to grandparents—even when grandparents lived outside the family home—and they filled an important need for assistance within their families. Two-thirds of the sample provided help in the form of ADLs and IADLs and they provided more help when their parents were engaged in greater number of hours of caregiving, indicating that parents rely on adolescent help to deliver needed assistance to grandparents with AD. In fact, the majority of adolescents in this sample (69%) reported doing something in the previous week to help their mothers with caregiving and 24.1% reported helping their fathers with caregiving tasks. Thus, rather than sitting by passively in observer roles, grandchildren are providing hands-on care, albeit not in
large quantities. Moreover, they are not providing assistance to alleviate parents’ emotional burdens, but they help because it is needed. These adolescents are filling a gap by supporting the effort of their parents so that the family may meet their grandparents’ needs. However, it is not clear how much support and preparation adolescents are given for this auxiliary role. The provision of assistance with intimate behaviors such as eating and grooming may require a more advanced level of maturity than many grandchildren are able to manage. Even assistance with IADLs presents significant challenges for young caregivers. Of particular concern is the percentage of grandchildren who reported helping with adult tasks such as taking medication and managing money, assistance which they might not be mature enough to give. Additionally, if adolescents are left on their own to provide this assistance, they could experience feelings of anxiety, embarrassment, and fear, outcomes that have been reported in other studies (Szinovacz, 2003). This quantity and nature of support and preparation are certainly dimensions of caregiving that should be explored further.

This study also considered the role that relationship quality plays in the provision of care. Results indicated that adolescents provided more help when they had greater affection for their grandparents. This finding is similar to those with adult caregivers (Cicirelli, 1993). Similarly, when grandchildren share positive relationships with their grandparents, they may find it easier to connect with them and be more willing to give assistance. It may be that adolescents who enjoyed positive relationships with grandparents prior to the diagnosis of AD are more inclined to help care for them as the disease progresses. Alternately, it may be that by spending more time with grandparents, adolescents develop greater affection for them. Some studies have shown that individuals who spend more time with older people generally hold more positive views of them (McPherson & Fitzpatrick, 2006; Pecchioni & Croghan, 2002). Longitudinal studies of changes in relationship quality and caregiving are needed to understand how this association evolves. Interestingly, the quality of adolescents’ relationships with their own parents was not important to the provision of care. This underscores the role of adolescent caregivers as a necessary pair of hands in the auxiliary support for the primary caregivers. Caregiving reverberates throughout the family system and adolescents help because it is needed, not because they feel especially close to their parents. Thus, adolescents’ feelings about grandparents, coupled with parents’ need for tangible help, predict the level of assistance that adolescents are willing to give. But how does the caregiving role affect adolescent development?
How Is Caregiving Related to Adolescent Development?

Adolescent caregivers live in a family ecology that models providing assistance to others. As such, it was expected that family caregiving responsibilities would contribute to a great sense of social responsibility for adolescents. This was not borne out in the present research. The direct, objective help that adolescents provided to grandparents did not result in greater social responsibility. However, their fathers’ experience of subjective caregiving burden did predict lower levels of social responsibility in adolescents. This was particularly surprising given that mothers provided more care. These findings indicate that fathers may play a primary role in the socialization of young people regarding the caregiving for grandparents. Perhaps when fathers feel stressed by the experience, they communicate the costs of caring to their adolescents, resulting in lowered adolescent commitment to others. The children may then feel that the costs are too high, and decide that it is not worth thinking about the needs of others. Alternately, it could be that when adolescents do not harbor much concern over their need to contribute to the good of society, their attitudes may create more caregiver stress for their fathers. The fact that this relationship emerged with fathers but not mothers suggests that fathers’ provision of assistance is more salient such that, even when minimal, adolescents take notice. Alternately, mothers’ caregiving responsibilities may be subsumed under the more general notion of mothers as “kinkeepers” for the family (Spitze & Logan, 1989) and their caregiving efforts may be taken for granted. Collectively, these findings suggest that caregiving should be included as a factor not only because it influences current levels of prosocial attitudes but also because it has long-term consequences for the establishment of values regarding care.

How Is Caregiving Related to Attitudes Toward Long-Term Care?

The ecology of caregiving was predicted to influence young caregivers’ attitudes toward long-term care and the care of their own parents in the future. Adolescents who provided more care to grandparents had more positive attitudes toward the provision of long-term care to older parents in general. These young caregivers may see the positive benefits of providing assistance to a grandparent, and project into the future that this will be a necessary component of their relationships with their own parents. The fact that these young people have experience providing care may make them more confident in their abilities to do so. Consequently, they may feel that
not only is it possible to do this for their own parents, but it is laudable to do so. However, the psychological burden they witness in their own parents seems to take a toll. Adolescents exhibited more negative attitudes toward long-term care when fathers experienced greater subjective burden; there was a trend in the same direction for mothers’ subjective burden. It may be that young caregivers experience positive feelings regarding their ability to make contributions to the caregiving situation, while at the same time recognize the emotional costs to providing such care through their observations of their parents. The unique role of fathers in this socialization process is worthy of further study.

**Plans for Future Care**

Finally, a primary concern regarding young caregivers’ experiences is how they might affect future plans for caregiving. Given the current demographics, families will need to rely on one another to provide needed assistance. Despite the stresses that families feel when providing care to a grandparent with AD, all the young caregivers in this study reported that they would take on the caregiver role for their own parents in the future with the majority indicating that that they would serve as the primary caregiver. It may be that the caregiving experience instilled in these young people a sense of competence and confidence in caregiving that they can take with them in the future. Of course, this could also reflect a selection factor such that families who were willing to take on the caregiving role when there were teenagers in the home may be fundamentally more committed to family ties than those who opt not to become caregivers. It is important that future studies consider this question of self-selection to caregiving. Perhaps it is the combination of the previous relationship and whether one can choose to be a caregiver that predicts whether there will be positive or negative outcomes. Longitudinal research with non-caregiving controls would serve to address this very important question.

**Limitations and Strengths of the Study**

Although this study provides a glimpse into the ecology of family caregiving for young caregivers, it suffers from a number of limitations including small sample size and low power, self-report measures, and assessments taken only at one point in time. Many studies of young caregivers have been conducted on small samples (e.g., Howard & Singleton, 2001; Shifren, 2008), due, in part to the difficulty in obtaining participation from highly stressed families,
especially in families with grandparents with AD. Small samples are underpowered, making significant relationships more difficult to find. However, examination of the effect sizes obtained in this study suggests that these relationships would be found in larger samples, as well. Use of a Bonferroni correction for family-wise error provided a stricter criterion for obtaining significance. Still, a fairly clear pattern emerged, indicating that there are connections between objective and subjective caregiving burden of parents, quality of relationship with grandparents, and adolescent prosocial outcomes.

Additional limitations include the use of self-report measures and assessments made at one point in time. Self-report measures are known to be biased and the manner in which questions are phrased affects the answers given (Schwartz, 1999). Additionally, the caregiving experience is an ongoing, highly dynamic one for each family member. Given that data were collected at one point in time, the findings represent a snapshot of a single time frame in the families’ caregiving careers.

The study exhibited strengths, as well. It used reports from multiple family members and considered a variety of dimensions of helping behaviors. By obtaining reports from multiple family members, a clearer picture of the ecology of family caregiving from the perspectives of parents and adolescents emerged. The inclusion of both objective and subjective burden measures allowed for a more detailed view of the impact of the challenges of caregiving on the young. Additionally, consideration of current prosocial attitudes and projections of anticipated behavior in the future provide some indication of the developmental trajectory these young caregivers are on. Future studies should consider following caregiving families as they move through the caregiving experience. They should continue to use multiple measures of constructs and obtain input from a variety of family members. Moreover, greater efforts should be expended toward enlisting more ethnic minorities in this research. Despite great efforts to obtain ethnically diverse samples, caregiving studies typically have difficulty enticing ethnic minorities to participate. This may be due, in part, to the greater sense of familism that ethnic minorities typically harbor (Gaines et al., 1997); they assume a personal responsibility for caregiving and do not relate to the European American views on “caregiving” which may involve the solicitation of help outside the family. Future studies should address these limitations by increasing the sample size and diversity, expanding on the use of multiple informants within a family, obtaining assessments of objective nonfamily members (e.g., social workers), and following families as they progress from the early years of AD caregiving to the later stages of the disease.
Conclusion

Caregiving for older people is rapidly becoming the norm for families in the United States. America is aging and as it does, more and more families will find themselves in the position of providing assistance to aging family members. Additionally, given that the course of AD often takes years, these families will be in need of a great many services for longer periods of time. Thus, it is important to support families as they assume caregiver roles. The research described in this article provides evidence that families not only turn to adult children and their spouses for care but also, to some extent, to the youngest, “forgotten” generation, as well. Future studies need to further examine caregiving by the young. This will allow researchers to articulate appropriate developmental boundaries for young caregivers and establish effective interventions to assist those who are drawn into the caregiver role.

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