Family Caregiving: The Positive Impact on Adolescent Relationships

Diane L. Beach, MPH
Adult children are a significant contingent of elder care providers; a number of these individuals simultaneously care for children of their own while coping with caregiving commitments. Unfortunately, there is a paucity of information regarding the caregiving impact on these children and young adults. Moreover, the possible positive consequences of caring for an impaired elder are rarely mentioned. The current study was undertaken to examine the potential positive caregiving experiences of adolescents and their perceptions of relational enhancement as a result of caregiving. Twenty adolescents aged 14—18 were interviewed and asked a series of semistructured questions concerning satisfaction related to caregiving. To be included, respondents had to be a child, grandchild, or niece/nephew of an Alzheimer's (or Alzheimer's Type Dementia) patient cared for by the adolescent's immediate family. Employing features of content analysis methodology, all interviews were audiotaped and transcribed verbatim. The results merged into four primary categories: 1) increased sibling activity/sharing; 2) greater empathy for older adults; 3) significant mother-adolescent bonding and 4) peer relationship selection and maintenance. The implications for future research and practice are discussed.

Key Words: Adolescents, Caregiving, Family relationships, Outcomes

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Most older adults afflicted with Alzheimer's disease live at home and receive 80—90% of their care from spouses and adult children (Brody, Johnsen, & Fulcomer, 1983; Cantor, 1983; Johnson & Catalano, 1983; Office of Technology Assessment, 1987; The National Alzheimer's Association, 1995). Consequently, the great majority of caregiving research has focused on the caregiving trauma experienced by spouses and adult children of elders afflicted with this disorder (Beach, 1993, 1995; Brody, 1989; Lee, 1985; Miller & Montgomery, 1990; Rabins, Fitting, Eastham, & Fetting, 1981; Stetz, 1989; Townsend, Noëlker, Deimling, & Bass, 1989; Williamson & Schulz, 1990; Young & Kahana, 1989). The overwhelming majority of these studies have focused on the primary caregiver alone, thus neglecting other family members such as husbands, adolescents, and younger children.

Recently, however, there has been a noticeable shift in focus from the primary caregiver in isolation to the entire family system (Cantor, 1992). Researchers have clearly outlined the need to examine the family in total to better ascertain the precise ways in which various family members are affected by informal caregiving (Brody, 1989; Ory, 1985). Despite this shift in focus, little attention has been given to young children and adolescents within the caregiving environment (Beach, 1994). The rare studies that have examined this phenomenon and its consequences for young adults have concentrated on the burden of caregiving with primary focus on peripheral stress associated with primary caregivers. For example, Creasey and Jarvis (1989) interviewed 29 grandchildren, each with a grandparent suffering from Alzheimer's disease living with them or nearby. Their parents also completed questionnaires that assessed their relationships with each other and the ill grandparent. Results indicated that grandchildren had a poorer relationship with their grandparents and their fathers if their mothers (the primary caregivers) were experiencing high levels of burden. A similar study documented the disruption of teens' social lives, stress between grandparents and grandchildren, and resentment of the mother's caregiving burdens (Brody, 1989). In a more recent inquiry, Pruchno, Peters and Burant (1995) explored negative perceptions of caregiving and documented no significant differences between mothers (primary caregivers) and their children with regard to negative elder reports as a result of caregiving responsibilities. Conversely, the children reported more negative elder behaviors than their fathers and also articulated greater caregiving satisfaction than either their mothers or fathers. To date, these are the few identifiable inquiries that have included an investigative component focusing on the child or adolescent in the caregiving setting. Unfortunately, these studies have primarily concentrated on the negative aspects of caregiving and on adolescent stress associated with the primary caregiver's experience. Overlooked are the possible positive experiences of young adults.
and children; this phenomenon is generally negated in the caregiving literature.

While other secondary caregivers (i.e., husbands and younger children) deserve more attention, older adolescents are at particular risk given their formation of identity and ego in this phase of the life cycle (Erikson, 1959). Previous studies have documented that adolescents will have a greater degree of ego identity than their younger counterparts (Protinsky, 1975) and that the affective quality of adolescent-parent relationships directly influences the adolescent’s exploration of ego (Papini, Sebby, & Clark, 1989). Additionally, it has been noted that adolescents who report greater perceived family fusion are less likely to pursue their own identity formation (Anderson & Fleming, 1986). The affective nature of parent-adolescent relationships are no doubt influenced when a family member with Alzheimer’s lives in the home environment, and it is quite possible that family fusion takes on a new meaning as a result of the caregiving predicament. Whether the consequences are positive or negative, families in the caregiving context tend toward more cohesion (fusion) which may, in turn, affect the teen’s ability to explore his/her own separate sense of self via sibling relationships, peer selection/maintenance, and parent-child detachment.

Importantly, demographic predictions ensure that adolescents will continue to be involved in the care of older adults. Currently, 75% of caregivers are female with an average age of 46; 31% of these women have children at home under the age of 12 and 23% live with a child aged 12–17 (National Center for Health Statistics, 1987). As such, it is imperative that this population be studied further; researchers and practitioners alike must have accurate assessments of these individuals. Specifically, 1) how does the caregiving environment alter adolescentOLDER adult relationships?; 2) does the caregiving context have a positive influence on adolescent-mother (primary caregiver) relationships?; 3) how do sibling associations weather the caregiving situation? and 4) do caregiving responsibilities influence peer selection? The current study addresses these questions and incorporates aspects of Grounded Theory Methodology to ascertain respondents’ subjective experiences. This methodology was selected in an attempt to bridge noticeable gaps in earlier research. Previous studies focusing on this population have incorporated quantitative methods to examine the consequences of caregiving; Likert-type scales are typically used to assess caregiving outcomes and to generate outcome scores. While interesting, these inquiries generate data that need further exploration to make conclusive observations. To that end, the current qualitative study was undertaken.

Methods

Sample Selection and Profile

A sample of 20 respondents was used for the study. In order to be included, respondents had to be the child, grandchild or niece/nephew of an Alzheimer’s or Alzheimer’s Type Dementia (ATD) patient living with the respondent’s immediate family. Study participants were recruited via the local chapter of the Alzheimer’s Association; to ensure the confidentiality of all families, potential respondents were notified of the study by support group leaders and instructed to contact the investigator if interested in participating. The demographic profile of informants showed the group to be mostly female (55%), with an average age of 18 years. The majority of respondents were Caucasian and had completed their high school education. Most respondents helped with the care of a grandmother followed by aunts or uncles, and fathers. The average age of the older person with Alzheimer’s disease was 69, and the majority of respondents resided with this older adult (see Table 1). Most participants said they were required to help with the bulk of caregiving responsibilities.

Design and Procedure

This was a nonexperimental study; features of content analysis methodology (Glaser, 1978) were employed to identify and describe the positive caregiving experiences of adolescents and young adults. This methodology was chosen because it is useful in ascertaining informants’ perceptions of experiences while limiting opportunities for the introduction of preconceived hypotheses.

Semistructured interviews were used to collect data on the experiences of the respondents; informed consent was obtained prior to commencement of all interviews. Questions probed for the respondents’ thoughts and feelings regarding Alzheimer’s disease, dementia, intergenerational relationships, and eldercare. Respondents were interviewed using the following open-ended queries:

Table 1. Respondent Demographic Profile

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<thead>
<tr>
<th>Table 1. Respondent Demographic Profile</th>
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<tr>
<td>Average Age of Respondent</td>
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<tr>
<td>Respondent Gender</td>
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<tr>
<td>Female</td>
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<tr>
<td>Male</td>
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<tr>
<td>Respondent ethnicity</td>
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<tr>
<td>Caucasian</td>
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<td>African American</td>
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<td>Native American</td>
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<tr>
<td>Pacific Islander</td>
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<tr>
<td>Average Age of ATD Patient</td>
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<tr>
<td>Patient’s relationship to the respondent</td>
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<tr>
<td>Father</td>
</tr>
<tr>
<td>Aunt or uncle</td>
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<tr>
<td>Grandmother</td>
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<td>Additional Respondent Characteristics</td>
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<td>• 64% had completed the 12th grade at the time of interview.</td>
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<td>• 55% had lived with AD patient for 5 years or more.</td>
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<td>• 82% said they were instrumental in caregiving.</td>
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<td>• 64% said they were contributing to the patient’s improved quality of life.</td>
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<td>• 93% said they picked up more household responsibility.</td>
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<td>• Mothers were most often identified as the primary caregiver (82%).</td>
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1) Tell me about your relationship with your parent, grandparent or aunt/uncle.

2) Have you noticed a change in your friendships now that your relative lives with you? Were any of those changes positive? Tell me about that.

3) Do you feel closer to your other family members now that your relative lives with you? If "yes," can you describe those changes?

4) Please describe how you faced the diagnosis of Alzheimer's disease.

5) Please describe how your family talks/talked about the illness.

Analysis

All interviews were audiotaped, transcribed verbatim, and analyzed using a 2-tier system of sorting and analysis (Glaser, 1978). Specifically, labels were assigned to segments of text allowing for the collection of related segments within and across interviews. To be considered representative, each category must have evidenced itself at least 3 times within each interview. This stage continued until no new codes were discovered. Responses within the representative categories were subsequently examined for similarities and differences.

To verify the data collected, a subsample of the participants (n = 5) were recontacted upon the completion of all interviews. They were asked to read a portion of their transcribed interviews and comment on the accuracy of their reported thoughts. Additionally, caregiving adolescents (who were not part of this study) were asked to remark on the extent to which they related to experiences described by the study participants. Lastly, analysis by colleagues independent of the study, but who work with young adults, (n = 2) were asked to comment on the informant's reported circumstances (as related to their own support group members' experiences).

Common Categories

Increased Sibling Activity/Sharing. — Most respondents (73%) described the caregiving situation as a mostly positive influence on their family relationships. Specifically, they said caregiving circumstances often necessitated spending more time with siblings. As articulated by the following young adult, older siblings (who lived away from home) became concerned about his caregiving responsibilities and made concerted efforts to spend time on the sibling relationship:

Well... They've been over and they have seen changes in him (the patient) and they've been over when he's gotten a little edgy... They worry about me, so every once in a while my brother or sister will come over and we'll do something. (Respondent #6, Male)

Other respondents detailed closer family bonding as a result of coping with patients' aberrant (yet expected) behaviors:

We were out to dinner one night and I was with my grandparents and there were some other family members there too. My grandma will ask the same question five times like incessantly and not realize she's doing it and so we just sort of... The only way we can really handle it is to just sort of laugh about it and say "Oh well, its just the way it is." We give each other funny looks. It helps to be able to relieve the tension through kidding each other. (Respondent #3, Female)

Finally, other study informants talked about positive changes in historically distant sibling relationships:

Well, my brother used to come down from Fullerton maybe once a month or once every 2 months. Now he comes down a lot and you know we go out with my Dad and then on Saturdays and Sundays, we'll go play racquetball or something like that (which we never had done). (Respondent #1, Male)

Greater Empathy for Older Adults.— Overwhelingly, the respondents commented on perceptual changes regarding older adults; 73% described themselves as more understanding of older people as a consequence of the caregiving predicament. As outlined by the following comments, these individuals reported feeling more comfortable and empathetic of the aging population in general:

I'm less hesitant to look negatively at someone who's had a stroke or something (especially when they are just glazed over and walking). It really doesn't phase me anymore. I don't think of them as being different. I'm more interested in looking out for them and seeing what their family is doing. (Respondent #10, Male)

Analogous to the comment below, respondents detailed their compassion regarding private behaviors in public settings:

There is really nothing you can do, you know? Before I left for college he was becoming incontinent where he couldn't get to the bathroom in time and he might have wet areas on his pants and that would bother me, but I wouldn't really be embarrassed for myself. I was more embarrassed for him because I know that he wouldn't want to be seen in public like that. (Respondent #8, Female)

One male respondent described the need to cultivate patience with his Grandmother's repetitive queries:

I was looking for a job just out of college... and every morning we would have the same conversation and I had to make light of it and just try to understand the disease. A typical conversation would be, "So Jason what are you going to do today?" And this would happen every morning "Well, I'm going to look for a job." "Oh, looking for a job, can't find anything?" "Nope, can't find anything." And she would say well what did you study? I studied finance and she would say you shouldn't have any problems finding a job. And then we'd talk about something else and she'd come back and say, "So, you still haven't found a job yet?" And I'd say, "No Grandma, we've been sitting here for the last 5 minutes talking about that." And we'd have this conversation every morning. I learned how to be patient. (Respondent #12, Male)
Significant Mother/Adolescent Bonding. — The majority of primary caregivers were identified as mothers (82%). The respondents made repeated reference to greater intimacy within the mother/adolescent relationship as a consequence of the caregiving predicament. Similar to other respondents, the following adolescent observed that positive reinforcement was given generously by his Mother:

I don’t give myself much credit for helping out, but my Mom is always reinforcing the idea a lot and I guess I do help, but she does so much. She takes care of everything. I basically just cart him around and that’s nothing. (Respondent #15, Male)

Similar to others, this respondent talked about being trusted enough to be “briefed” on the more serious aspects of caregiving:

She tells me everything that’s going on because if anything happens to her, then its kind of me . . . There’s no way that I can handle everything that she is telling me, it’s just too much. She’s got so much taken care of . . . If something happens to her, there’s things that I have to do. I just know that there is a drawer where there’s all this stuff that I have to see. We are close because she keeps me involved. (Respondent #20, Female)

Other respondents described working through emotional outbursts and burnout experienced by their Mothers:

She’s always been a person who doesn’t complain a lot and just kind of bickers up and does whatever needs to be done. But I’ve caught her crying before and stuff like that. I just said to her, “Listen, this is tough, it’s tough on everybody, but your bearing most of the burden, so its especially tough on you.” I tried to offer more help because I thought that’s what she needed. (Respondent #19, Male)

Further, respondents articulated a genuine desire to spend time with their Mothers during a time when family bonding is not necessarily “fashionable”:

I’m past the “I don’t want to hang out with my parents stage.” This has made us closer. Now, when she comes home, she talks to me because she tells him everything, but she’s not going to get any responses from him and you need responses when you’re telling somebody something. She tells me everything and she’ll just go on and on and on and I don’t even think it matters really if I listen. I mean it does, but as long as I’m just appearing to listen. I just feel closer to her. (Respondent #14, Male)

As noted by the following comments, these individuals disclosed greater appreciation and respect for their caregiving mothers:

She was always under a lot of pressure and a lot of stress because care taking is very difficult. I didn’t realize it until I actually saw it and lived with it for several months. It’s a bear and as a result she struggles a lot. It’s a treat for her just to get out of the house. (Respondent #4, Female)

Peer Relationship Selection and Maintenance. — Adolescence tends to be a period of significant peer bonding and simultaneous disengagement from the family unit (Gray, 1989). The caregiving situation appeared to make a significant impact on this pattern and the respondents’ selection of peers. As discussed by the following individuals, having friends at the house (where the patient resided) necessitated the selection of empathetic peers:

He might be in a good mood one day and he wouldn’t be yelling at my friends per se. A lot of time they would enjoy it because he’d ask them twenty times, “What’s your name, what’s your name?” and they would get a kick out of that, so most of the time it was pretty cool. (Respondent #5, Male)

I wouldn’t probably be friends with anyone who wouldn’t be able to handle it. If I went to someone’s house and they had a relative with dementia or whatever, I would be comfortable there. So, I’m so used to it now. I feel like there’s no reason why they should be uncomfortable. (Respondent #9, Female)

Further, the informants learned how to openly discuss the situation with their friends to prepare them for visitations:

I’d say, “Well, I just want you to know when you come over, this and that may happen . . . They say, “OK, no big deal.” They don’t really see my Dad in a bad state. They just see him kind of out of it. (Respondent #2, Female)

As detailed below, respondents also described their friends as more objective regarding caregiving challenges:

My friends knew, but a lot of times I would get so mad I’d take it out on them and they would say, “Well, he’s sick, Shannon.” They were the ones who were telling me that. And now a lot of them go to the nursing home to visit him . . . A lot of them understood if I couldn’t go out. They might be upset, but they knew what was going on. (Respondent #16, Female)

Discussion

Data from this preliminary study suggest that a number of positive outcomes are experienced by adolescents and young adults intricately involved in caring for an older adult afflicted with Alzheimer’s disease.

Respondents reported that caring for a relative with AD increased the number of opportunities for more productive sibling interactions. Older siblings (not living in the home environment) expressed concern regarding younger caregiving brothers and sisters and therefore gravitated homeward for more regular visits. Contrary to previous findings, when caregiving conflicts presented themselves, direct conflict management techniques were repeatedly employed. Prior research demonstrates that adolescent siblings most often practice withdrawal as a conflict resolution technique and avoid direct dialogue altogether (Creasey, 1993). However, the urgency of the caregiving situation led these respondents and their siblings to work out differences more quickly via direct dialogue.

The results also illustrated a change in perceptions
and attitudes regarding the aging sector of the population. Study participants overwhelmingly described themselves as more empathic with older adults and their health problems. During times of stress, female adolescents have been described as more successful in retaining relationships with elders and have demonstrated greater empathy for older adults as compared to their male counterparts (Laursen, 1993). Data from the current study revealed that both female and male adolescents experienced positive relationships with their ill relatives and possessed equal empathy for older adults in general. Respondents in the study also described themselves as increasingly patient with the repetitive (and often bothersome) behaviors frequently demonstrated by the older adult with AD. Embarrassing behaviors (i.e., incontinence) necessitated the development of yet more effective coping strategies.

Adolescents and young adults manifest significant reliance on peers during this phase of life (Clark-Kempers, Lempers, & Ho, 1991; Laursen, 1993). Earlier research suggests that male adolescents differ from their female counterparts and solicit verbal support from friends less frequently (Shulman, 1993). Counter to those data, results from the current study indicated that females and males equally sought verbal support from peers. Respondents in this study did, however, repeatedly detail changes in the evaluation and selection processes pertaining to those relationships. Analogous to earlier findings, they recognized the impermanence of their peer associations (Laursen, 1993) and were less tolerant of inappropriate or insensitive behaviors.

Earlier research has documented a stepwise reduction in the importance of adolescent relationships by age; early adolescents (ages 11–13) have previously rated their peers as significantly more important when compared to their older counterparts (ages 14–19; Clark-Kempers et al., 1991). Supporting this trend, it is quite possible that this sample (x = 18 years) was less devoted to their peers, and consequently, more proactive about their attitudes regarding their older relative; friends were chosen who demonstrated understanding and empathy toward the family member. As detailed by several respondents, peers who were insensitive to the situation were no longer invited to the home, and they systematically became less important attachments.

The most pivotal emergent category was that of the mother/adolescent relationship. As noted previously, the majority of primary caregivers were identified as mothers and respondents repeatedly described those relationships as closer due to the caregiving predicament. More specifically, respondents stressed that their mothers were sincerely appreciative of their help and willing to issue positive reinforcement and verbal praise for caregiving assistance. Mother caregivers consistently initiated open dialogue with their children regarding the patients’ care plans, without omitting even the more painful details; these young adults became the mothers’ confidants, assisting them through a myriad of emotional outbursts. Surprisingly, this additional relational pressure appeared not to produce significant problems (most respondents overwhelmingly outlined a desire to spend time with their Mothers, describing a genuine respect and appreciation of their caregiving responsibilities). Similar to previous findings (Greenberg, Siegel, & Leitch, 1983; Hamill, 1994), adolescents in this study demonstrated greater maturity than their non-caregiving contemporaries, thus enjoying better communication with their mothers. Intriguing as it is, this personality trait must be traced: did the caregiving experience create a more mature adolescent, or was this sample more emotionally sophisticated to begin with?

In sum, these results individually and collectively raise questions that may have implications for adolescent ego development and identity formation. Counter to previous work (Anderson & Fleming, 1986), greater family fusion within the caregiving environment appeared to facilitate (not deter) from the adolescents’ identity exploration. Respondents in this study expressed more positive regard for their siblings and appreciated the extra measure of time spent on those relationships. Relationships with their mothers were also described as closer and having greater mutual respect; the adolescents embraced additional time spent with their parental caregivers. Lastly, the respondents overwhelmingly articulated the need to be assertive and selective with their friends and said they were significantly more understanding of older adults as a result of the caregiving experience. Given these outcomes, it is quite plausible that caregiving experiences contribute toward more (not less) identity exploration; study participants were repeatedly granted opportunities to carve out relational philosophies (which often gravitated against their cohort’s relational norms) and expressed pride in their decision-making skills. Clearly, these issues warrant further investigation.

It must be further reiterated that these data are preliminary and somewhat limited in scope due to the small sample size. Data for the study were gathered from narratives (retrospectively reported) exclusively by adolescents. Future studies should address both the adolescent’s and the primary caregiver’s perceptions of the caregiving environment. These longitudinal studies will provide additional sources of information from which to assess family caregiving systems. Additionally, the informants in this study were mostly Caucasian with an average age of 18; the majority of respondents identified the primary caregiver as a mother. Researchers need to assess adolescent caregivers of diverse ethnic backgrounds, different relationships to the primary caregiver, and various age groups. It is possible that perceptions of positive caregiving outcomes are influenced by ethnicity, the relationship to the primary caregiver, and age.

Despite these limitations, it is clear that a number of positive outcomes are possible for young adults coping with family caregiving. The respondents in this study indicated that an active role was taken (and expected) in caring for the demented family member. Changing U.S. demographics and the postpone-
ment of childbearing ensure that the trend of active adolescent caregiving will continue and likely increase. Consequently, researchers and practitioners alike must be cognizant of the negative, burdensome effects of caregiving as well as potential positive consequences for this unique population.

References


Received October 1, 1996
Accepted October 6, 1996