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GIVING UP AND GIVING IN: YOUNG ADOLESCENTS'
DILEMMAS WHEN CARING FOR A GRANDPARENT
WITH ALZHEIMER'S DISEASE

by

Diane Lee Beach

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Education

University of San Diego

1999

Dissertation Committee

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ABSTRACT

Giving Up and Giving In: Young Adolescent's Dilemmas When Caring for a Grandparent with Alzheimer's Disease

Caregivers of persons with Alzheimer's disease have been studied extensively; the vast majority of caregiver research has focused on spouses and adult children, negating the impact caregiving has on younger family members. Importantly, 75% of caregivers are female; 31% of these women have children at home under the age of 12 and 23% live with a child aged 12-17. As such, adolescents will be increasingly involved in the care of Alzheimer's victims. This study sought to examine the experiences of these individuals. Specifically, what is it like for an adolescent to provide care for a grandparent afflicted with Alzheimer's disease?

A qualitative, grounded theory study design was utilized. Ten adolescents aged 11-18 were interviewed and asked a series of semi-structured questions regarding caregiving. To be included, respondents must have been the grandchild of an Alzheimer's victim cared for by the adolescent's immediate family. Taking into consideration key elements of the ethnographic interview, grand tour, descriptive, structural, and contrast questions were integrated throughout the interview guide. More specific questioning and probing strategies were also designed which explored the perceptions of these adolescents with regard to their rewarding and nonrewarding caregiving experiences.

Employing features of content analysis methodology, all interviews were audio-recorded and transcribed verbatim. First, open coding of the data was conducted. Second, selective coding of the data was generated. Using the core variable as a guide, examination of the data for conditions and consequences directly related to the primary category, "Challenging the Continuum of Change," was further evaluated for similarities and differences across interviews. The subcategories identified via this content analysis process included (a) A Missing Voice, (b) The Changing Family, (c) Coping, and (d) Reaching Out. Conditions falling under these subcategories included: Recognizing the Difference; She's There, She's Not There, Reversal of Blame, Increased Family Intimacy, Loss of Sibling Trust/Sibling Inequality, Parental Conflict, Accepting the Changes, Holding Back Frustrations, Self-Induced Isolation, Confiding in Friends, Altered Leisure Activity, and On Your Best Behavior. Discussion points focus on future research and practice with regard to caregiving adolescents. In short, how can we help these young adults as they challenge the continuum of change and progress through this tenuous phase of their lives?

DEDICATION

For my Mammaw:

Josephine Nardella Scruggs

ACKNOWLEDGEMENTS

I thank my family members who have been there through this long, sometimes trying process: Wayne, Brandon, Mom, and Dave. You have each been supportive and inspiring in your own way. Your loving sacrifices have allowed me to complete this journey.

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I want to acknowledge all of the respondents in my study. Thank you for your willingness to share your experiences and to help with this project. May your stories help others in this predicament and may your own pain be eased.

Finally, to all families who struggle through this process. The commitment to your loved one afflicted with this devastating illness will never go unnoticed. May the “long goodbye” be eased in knowing that your caregiving is the ultimate statement of unconditional love.

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CHAPTER I

THE PROBLEM

Statement of the Problem

Alzheimer's disease (AD), the most common cause of dementia, represents one of the major sources of impairment among older persons (Cohler, Groves, Borden, & Lazurus, 1989). Approximately 4 million Americans currently have AD and unless a cure or successful prevention strategy is discovered, estimates suggest that as many as 14 million individuals will have the illness by the middle of the next century. Prevalence rates increase dramatically with age such that nearly half those 85 years of age and older are diagnosed with probable AD (National Alzheimer's Association, 1995). Given the rapid growth of this age group and other demographic predictions, such trends pose both present and imminent concerns to both formal and informal caregivers of older persons. Importantly, 75% of caregivers are female; 31% of these women have children at home under the age of 12 and 23% live with a child aged 12-17 (U.S., Bureau of the Census, 1987). As such, adolescents will be increasingly involved in the care of AD victims. The proposed grounded theory study seeks to examine the experiences of these individuals.

Symptoms of Alzheimer's Disease

Alzheimer's disease is defined as a progressive, degenerative disease of the brain, and is the most common cause of dementing illness. The cause is unknown, and as of this writing there exists no cure (National Alzheimer's Association, 1995). The central difficulty in providing care to victims of AD is that the disorder causes an insidious and gradual loss of an individual's physical and mental functioning. In the early stages of the disease, an individual's memory and complex thinking are impaired. However, as the disease progresses, the person's ability to understand and respond appropriately to the world around him/her is impaired as areas of the brain essential for impulse control and emotional stability are also damaged (Gruetzner, 1988). Symptoms of the disease include: (a) gradual memory loss, (b) disorientation to time and place, (c) decline in ability to perform routine tasks, (d) impairment of judgment, (e) personality changes, (f) difficulty in learning, and (g) loss of language skills. Persons with AD have trouble communicating with others and exhibit strain with word finding and other functions related to language, known as aphasia. Moreover, they are unable to recognize or use objects appropriately due to the condition defined as agnosia (Gruetzner, 1988). These physiological changes to the brain are also associated with aberrant behaviors such as agitation, aggressive or assaultive behaviors, wandering, and incontinence. As the disease progresses, a person with AD will lose control of physical functions (such as the ability to ambulate) and victims may suffer from secondary infections and other excess disabilities which add to the burden of caregiving. The total

progression of AD will usually last an average of 8 years but can extend as long as 20 years (U.S., Congress, Office of Technology Assessment, 1990).

Risk Factors

The etiology of AD remains unknown, but several risk factors and predictors of AD have been identified. First, results from previous studies suggest that cognitive reserve (or increased educational attainment) may be protective of AD (Stern, Brandt, & Albert, 1996). Specifically, increased educational attainment and cognitively demanding occupations are associated with lower risk of acquiring the disease; this level of achievement may induce a “cognitive reserve.” Individuals with greater reserve function longer, despite the onset of the disease. Other research has documented the association between cognitive reserve and brain size. Specifically, brain size prior to the onset of AD may delay the onset of symptoms (Schofield, 1995).

In addition to data regarding protective characteristics, researchers have identified potential risk factors for the development of AD. A history of AD in a first-degree relative (parent or sibling) increases the possibility of developing the illness four-fold. In addition, a severe head injury resulting in a period of unconsciousness doubles the risk of developing the disorder (Khachaturian & Radebaugh, 1996).

Treatment of Alzheimer’s Disease

While no cure has been found for AD, two new drugs are currently being used to treat AD victims. Cognex (tetrahydroaminoacridine or tacrine), the first AD drug approved by the Federal Food and Drug Administration, slows the progression of the

disease. Cognex works by slowing the breakdown of acetylcholine, a nerve cell communicator. Increasing the amount of this chemical enables the nerve cells in AD patients to communicate more efficiently, and as such, some of the memory impairment observed in patients may be relieved. While encouraging, Cognex has only been studied in patients with mild to moderate dementia who were in otherwise good health (National Alzheimer's Association, 1997).

Donepezil (E2020, Aricept), an experimental drug, is currently being evaluated with regard to symptom reduction among AD patients. Phase three clinical trials have revealed that Donepezil improves cognition among patients with mild to moderate AD. Specifically, Donepezil inhibits the production of acetylcholinesterase, an enzyme present in the brain. Its job is to reduce the amount of acetylcholine, a substance that transmits nerve impulses to the brain. Because there is not enough acetylcholine in the brains of AD patients, it is hoped that by inhibiting the production of acetylcholinesterase (via Donepezil), symptoms will be improved among victims of AD (National Alzheimer's Association, 1997).

The Cost of Alzheimer's Disease

The cost of AD to the family has been well documented. The average lifetime cost of care to a person with the disease is \$174,000, with the annual cost of nursing home care for a person with AD averaging \$42,000. In most cases, these costs are paid for entirely out of pocket until the victim has exhausted his/her resources. As such, families make significant sacrifices both emotionally and monetarily; 70% of caregivers contribute part of their personal income or savings toward the victim's care.

Moreover, 31% of caregivers quit their jobs to provide care for the patient and 60% of employed caregivers miss days of work due to caregiving. The fallout results in an estimated \$11.4 billion to \$29 billion loss to employers each year due to shortened or interrupted days, decreased productivity, and replacement of employees who leave their jobs (Alzheimer's Association, 1996).

Caregiver Research

The early stages of the disease process require only minimal caregiver assistance for the patient. However, as the disease progresses, problems associated with the needs of the dementia victim increase, ultimately placing the demand of constant supervision on the caregiver. In most cases, this caregiver is a close family member; 80-90% of AD victims receive their care from spouses and adult children (Brody, Johnsen, & Fulcomer, 1983; Cantor, 1983; Johnson & Catalano, 1983; U.S., Congress, Office of Technology Assessment, 1987; National Alzheimer's Association, 1995). As a consequence, 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; Beach, 1995; Brody, 1989; Lee, 1985; Miller & Montgomery, 1990; Rabins, Fitting, Eastham, & Fetting, 1981; Stetz, 1989; Townsend, Noelker, Deimling, & Bass, 1989; Williamson & Schulz, 1990; Young & Kahana, 1989). The bulk of studies have focused on the primary caregiver (most often a wife or adult daughter) and have not examined the impact on adolescents or younger children.

Recently, however, there has been a noticeable shift in focus from the primary caregiver in isolation to the entire family system as the unit of analysis (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 few 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 AD living with them or nearby. 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 teen social lives, stress between grandparents and grandchildren, and resentment of 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.

While this small body of caregiver research has focused on adolescents, there is clearly much more to know about the caregiving experiences of this unique population. In particular, to what extent is identity development influenced by the caregiving experience? Previous research has documented the fact that older adolescents may be at particular risk given their formation of identity and ego in this phase of the life cycle (Erikson, 1983). 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 influence the adolescent's exploration of ego (Papini, Sebby, & Clark, 1989). Additionally, it has been noted that adolescents who report greater perceived family cohesion 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 AD 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.

Summary

Adolescents will continue to be involved in the care of dementia victims (as evident from demographic predictions). 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 (U.S., Bureau of the Census, 1987).

In San Diego County, there are approximately 40,000 individuals diagnosed with AD. Relying on national projections (i.e., 70% of victims are cared for at home by an adult daughter and 23% of these women have children aged 12-17 years), there are likely between 4,000-5,000 caregiving adolescents in San Diego County. Given these growing numbers (both nationally and locally), it is imperative that this

population be studied further; researchers and practitioners alike must have accurate assessments of these individuals.

Additionally, this study is of vital importance to the discipline of gerontology. Over the past 15-20 years, significant strides have been made in the field of AD caregiving. A progressive line of inquiry has been developed with regard to spousal and adult child caregivers and peripheral areas of caregiving have been the focus of prior research. These include, but are not limited to adult day care, ethical dimensions of caregiving, death and dying related to AD, quality of life in assisted living, long-term care reimbursement, and nursing home placement. Missing, however, are lines of direct and peripheral inquiry regarding the “hidden” caregivers: children and young adolescents.

The current study seeks to bridge this noticeably absent theoretical link and asks the following:

1. What is the adolescent’s experience regarding the care for an elderly family member afflicted with AD?
2. How does involvement in the caregiving environment alter adolescent-elder relationships?
3. How do caregiving responsibilities affect the adolescent “experience”?
4. What impact does the caregiving environment have on the teen’s sense of self?

The current study addresses these questions by incorporating aspects of grounded theory methodology (Glaser, 1978) to describe adolescents' caregiving experiences.

CHAPTER II

REVIEW OF THE LITERATURE

The victim of AD suffers not in isolation; the entire family unit is impacted by this devastating illness. As such, the literature focusing on (a) spouses, (b) adult children, and (c) adolescent caregivers of AD victims will be reviewed. In addition, the intergenerational relationship literature that concentrates on grandparent-grandchild relationships will be examined. Clustered into two primary topic areas, the following concept areas will be examined: (a) attachment to the grandparent, and (b) interaction and frequency of contact with grandparents. Finally, the literature on adolescent development will be outlined. Specifically, the literature focusing on identity exploration, risk taking, and family stress as it relates to adolescent development will be examined. In the summary section, connections will be made between family functioning in the caregiving context and adolescent development. The need for the proposed study will be outlined.

The Caregiving Experience

Most caregiving is provided for by female family members with little help from others (Brody et al., 1983; Cantor, 1983; Hess & Soldo, 1985; Johnson & Catalano, 1983). Specifically, 72% of all primary caregivers are female with daughters and wives constituting 29% and 23% of this population, respectively (U.S. Senate, Special

Committee on Aging, 1990). Data from the Long Term Care Survey indicate that females are more likely to experience emotional strain associated with the caregiving role, as compared with their male counterparts. In fact, over 50% of wife caregivers reported significant emotional strain associated with caregiving as compared to husbands. Moreover, almost one-half of the daughters reported experiencing emotional strain, as compared with sons. Collectively, caregivers suffer from a myriad of psychosocial stressors including fatigue, anxiety, depression, and other stress-related symptoms (Cantor, 1983; George & Gwyther, 1986; Johnson & Catalano, 1983; Zarit & Zarit, 1982).

Caregivers also suffer from compounded stress precipitated by increasing financial pressures associated with caregiving. Because most public health payment mechanisms (i.e., Medicare and Medicaid) favor long-term nursing home care and short-term acute hospital care, most elderly individuals must use most of their own monetary resources to pay for long-term care services. Only when elderly family members are completely impoverished ("spent down"), will Medicaid provide monetary assistance for long-term care (U.S., Senate Committee on Aging, 1990). Even so, such mechanisms favor institutional care and generally do not pay for in-home services. As a result, family caregivers must also accept the financial responsibilities associated with caregiving if they choose to keep their elderly family member(s) at home. Despite these high levels of financial and emotional stress, most caregivers report that they will not relinquish the job or seek assistance from others until they are completely exhausted or until the patient is incapacitated (Young & Kahana, 1989).

Spousal Caregivers: Husbands and Wives

Research shows that female spousal caregivers tend to accept the role of caregiver as a normative stage in life and tend to provide more care (hour for hour) and provide a greater range of caregiving tasks as compared with their male counterparts (Miller & Montgomery, 1990; Tennstedt, McKinlay, & Sullivan, 1988; Young-Hess & Soldo, 1985). Additionally, this group of caregivers seem more resistant to sharing the responsibility and often do so only when physically or mentally exhausted and/or when the patient is completely disabled (George & Gwyther, 1986; Townsend & Noeleker, 1987; Townsend et al., 1989; Wilson, 1990). Consequently, female spousal caregivers are at greater risk of endangering their own health due to their age (generally older) and prior health conditions which tend to be poor (Wilson, 1990; Young & Kahana, 1989).

Research results also suggest that wives limit activities more than husband caregivers (52% of wives and 36% of husbands) and that wives tend to have fewer backup helpers and greater time pressures (Miller & Montgomery, 1990). According to the 1982 National Long Term Care Survey, 80% of spousal caregivers do not receive any assistance from their children. This finding was upheld in a study by Pruchno and Resch (1989) suggesting that most daughters and sons do not assist with caregiving responsibilities (53% and 69%, respectively) and that the burden of care most often lies with female spouses. Moreover, research indicates that wife caregivers are less likely to access professional services including home-delivered meals and in-home nursing services, as compared with male spousal caregivers. Not surprising, wives tend to report more subjective stress associated with caregiving when compared

with husbands (Barusch & Spaid, 1989). This finding suggests that a dose-response relationship exists between number of caregiving tasks and levels of reported stress.

Spousal Caregivers: Depression, Anxiety, and Coping

Studies have demonstrated both negative and positive consequences for this population of caregivers; addressing issues such as burden depression, anticipatory grief, physical health deterioration, and increased intimacy among husbands and wives (Beach, 1993; Fengler & Goodrich, 1979; Zarit, Reeves, & Bach-Petersen, 1980).

Walker and Pomeroy (1996) conducted a study of 100 caregiving spouses in an attempt to distinguish between depression and anticipatory grief. Using the Grief Experience and Beck Depression Inventories, the researchers refuted data in previous studies that demonstrated a depression effect by caregivers. Conversely, data from this study suggested that spousal caregivers were more likely to suffer from anticipatory grief as opposed to clinical depression. Fuller-Jonap and Haley (1995) surveyed 52 male spousal caregivers of AD victims and compared results with 53 demographically similar control subjects. These caregivers demonstrated higher levels of depression (in addition to increased respiratory problems, and more health habit difficulties in general). Similarly, Lichtenberg and Barth (1990) used a longitudinal design and interviewed 40 caregiving spouses at different stages of the caregiving process. Results indicated that the *stage* of caregiving was the most salient predictor of caregiver depression. Specifically, those caregivers with patients at home or recently placed in a nursing home were the most vulnerable to depressive symptoms. Another investigator

(Barber, 1993) has detailed the impact of institutional placement on caregiver depression. In this particular study, 105 spouses caring for victims of AD victims in the home environment versus the nursing home were compared. Results indicated that caregivers of institutionalized patients experienced negative consequences similar to those caring for victims at home. Specifically, the data demonstrated that caregiver stress is maintained due to on-going contact between caregiver and patient even after placement.

Recognizing the existence of depression among caregivers has led others to study the effects of spirituality and its impact on depression among care providers of AD victims. In a recent inquiry, Robinson and Kaye (1994) examined spiritual perspective and social support with regard to depression among 17 caregiving spouses of AD victims and 23 noncaregiving spouses of relatively healthy husbands. Contrary to preconceived hypotheses, the investigators found spiritual inclination to have no significant impact on social support or depression among caregivers. Interestingly, employment and increased access to support services were associated with decreased depression in caregivers.

Social support and the prevalence of depression among caregivers has also been a topic of inquiry. In a recent study (Monahan & Hooker, 1995), 51 spousal caregivers were assessed. Multivariate analyses indicated that higher levels of perceived social support were significantly related to better health among caregivers, while higher levels of neuroticism were significantly related to poorer health among caregivers. With regard to social support and depression, research on spousal caregivers' use of social

networks has also been undertaken (Carlson & Robertson, 1993). These investigators sought information on subjective and objective burden related to caregiving and how these factors related to social networking. Thirty-eight spousal caregivers of AD victims were interviewed; results demonstrated that subjective burden was positively associated with tangible assistance and frequency of contact with family members.

In addition to social support and spirituality, coping mechanisms used by spousal caregivers have been the focus of empirical inquiry. Social-emotional adjustment and coping strategies used by spousal caregivers aged 53-88 were most recently examined as they related to care providers of AD victims (Rose, Strauss, Neundorfer, & Smyth, 1997). Results indicated that caregivers were most frequently defined as over socialized (high distress and high self-restraint) and repressive (low distress and high self-restraint). A higher percentage of women were classified as over socialized compared to their male counterparts. High distress caregivers were also more likely to use emotion-focused coping strategies (such as wishfulness) compared to low distress caregivers who were more likely to use acceptance and instrumental coping strategies such as problem-focusing. Hooker, Frazier, and Monahan (1994) also examined personality coping strategies of spousal caregivers. These caregivers lived in the same home with their spouses having received a formal diagnosis of AD or a related dementia. Using the NEO-Factor Inventory and a revised version of the Ways of Coping Checklist, subjects' specific personality coping traits were analyzed. Results indicated that subjects scoring higher on the Neuroticism scale were less likely to use problem-focused coping strategies compared to more emotion-focused strategies. Conversely,

subjects scoring higher on the Extroversion scale were more likely to seek social support while depending less on emotion-focused coping strategies.

Caregiver coping mechanisms have also been looked at from an intervention perspective. In a study regarding joint storytelling (Kemper, Lyons, & Anagnopoulos, 1995), personal narratives were collected from AD victims and their spousal caregivers. Solo narratives were first taken from the victims and their spouses separately. Subsequently, joint narratives were elicited from each pair. The data analysis effort compared the ability of the AD victim to spontaneously recall settings, participants, and episodes via solo narratives with their ability to provide such details when prompted by their spouses during their joint story-telling. Results indicated that the AD victims had fewer problems with word finding during the collaborative story-telling as compared to their solo efforts. Quayhagen and Quayhagen (1996) sought to improve life-quality among victims of AD. Using 10 spousal caregiver-AD victim pairs, cognitive remediation intervention techniques were used to interrupt the progress of dementia. Results indicated that the phases of discordance, equilibrium, regeneration and emergence indicated a positive movement by victims and caregivers from a state of depleted interaction to a regaining of family life.

Adult Child Caregivers: Daughters and Sons

While adult child caregivers are younger and tend to be physically healthier than spousal caregivers, they too experience significant stress associated with family caregiving. Specifically, female adult child caregivers report significant role conflict and as they experience difficulty balancing current family obligations (i.e., raising young

children), professional life, and primary caregiving (Brody et al., 1983; Horowitz, 1985). As noted earlier, 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 (U.S. Bureau of the Census, 1987). The multiple responsibilities encountered by this group are overwhelming, and as such, this “sandwich” generation of both adult daughters and sons has been the focus of much discussion in the literature (Brody, 1981; Green, 1991; Johnson & Fulcomer, 1983; Miller & Montgomery, 1990; Rosenthal, Mathews, & Marshall, 1989; Spitze & Logan, 1990).

Most studies indicate that while both sons and daughters are involved in the care of elderly parents, distribution of tasks and time spent on caregiving differ significantly between these two groups (Cantor, 1983; Green, 1991; Horowitz, 1985). Stoller (1983) noted that caregiving sons and daughters differ most evidently with reference to domestic tasks. Additionally, researchers have noted significant variability in the actual hours of time spent in “assistance” activities between sons and daughters with the latter spending more time hour for hour in caregiving activities (Barusch & Spaid, 1989).

In terms of employment, studies show that full-time employed sons spend significantly less time caregiving as compared to “full-time” employed daughters. Because women tend not to reduce outside workloads and other responsibilities while caregiving, they experience significantly greater role conflict associated with caregiving as compared to caregiving sons (Miller & Montgomery, 1990). Employment status and education being equal, caregiving daughters still provide more care hour for hour than their male counterparts. Additionally, daughters are equally involved as care

managers. Males tend to hire outside assistance for caregiving and manage this care; women tend to manage care *and* provide technical assistance (Finley, 1989). In a large community study of elderly widows, researchers noted that the clear majority of care for elderly widows was provided by daughters and that the amount of care remained the same regardless of outside employment obligations and access to outside services (Brody & Schoonover, 1986).

Adult Child Caregivers: Role Taking, Depression, and Coping

Other research on adult child caregivers has examined “who” becomes the caregiver among siblings (Globerman, 1995). In a study of 54 caregiving and noncaregiving adult children, differences were documented with regard to focus, suffering, and experience of caregiver burden. Specifically, the investigators found childhood reputation to follow individuals into adult life. These caregivers described their roles as fully expected by other siblings and entrenched in family history. Siblings “excused” from responsibility in the past appeared to be uninvolved as adults when faced with caregiving tasks. Semple (1992) also examined siblings, but concentrated on family conflict regarding the patient. Using a sample of 555 caregivers, family conflict scales were developed to assess caregiving outcomes as they related to dynamics within the family. Results indicated that conflicts among siblings’ attitudes and actions toward the primary caregiver were associated with greater depression among caregivers. Additionally, conflicts focusing on behaviors toward the victim of AD were most likely to result in anger on the caregiver’s part.

Much of the research on adult child caregivers has concentrated on depression, burden, loss of self, and coping strategies. Wullschelger, Lund, Caserta, and Wright (1996) found that higher levels of burden were associated with increased anxiety about aging. This association was particularly strong for subjects who had recently placed their parent in a nursing home. In a similar study of adult child caregivers (Cohen, Lichins, Eisdorfer, & Paveza, 1990), researchers compared the prevalence of depressive symptoms and impairment due to psychiatric symptoms among caregivers of AD victims. Thirty-nine percent of daughters and 25% of sons reported significant distress. However, one-half of the daughters sought counseling as a result, while only 10% of son caregivers followed suit. As outlined in a 1992 study of adult child caregivers (Skaff & Pearlin, 1992), this distress is often caused by the caregiver's reported loss of self. Results from the study indicated that loss of self is most often caused by limited social contact and lack of social roles outside the caregiving role. Not surprisingly, loss of self was also significantly associated with lower self-esteem and greater depressive symptoms among these caregivers.

Adolescent Caregivers

Teens involved in the care of a demented family member have been rarely studied. While they are increasingly involved in the care of a relative with AD, this population has received little empirical attention. In an in-depth review of the literature, only five studies of adolescent caregivers of AD victims were identified (Beach, 1994, 1997; Creasey & Jarvis, 1989; Pruchno et al., 1995).

A group of researchers in Great Britain, The Young Carers Research Group, has looked at a population of young caregivers. However, these respondents were caring for elderly *parents* afflicted with a variety of illnesses such as Huntington's, parkinson's, AIDS and AD; distinctions were not made between disease groups. In a 10-month study of 15 young caregivers (average age=13 years) (Aldridge & Becker, 1993), semi-structured interviewing techniques were employed to access experiential data. The following findings were outlined: (a) the respondents revealed a significant commitment to their caregiving role despite neglect by other family members and professionals; (b) tasks performed by the young caregivers ranged from cleaning and preparation of meals to intimate activities such as toileting, showering, and dressing; (c) networks of formal and informal (social) support were quite limited for this population; the parent often elected one child to serve as caregiver and other family members and siblings were happy to relinquish the role; (d) peer relationships and social lives were severely restricted; career-oriented activities and aspirations were also curtailed as the role of caregiver was all-consuming, and (e) the majority of young caregivers were consistently late for school and/or took a large amount of time off of school to plan/monitor caregiving activities. Despite the major role of caregiving taken by these young individuals, the researchers found that they were never directly involved with any professionals regarding their parents' care (i.e., care planning by physicians, nurses, social workers).

Focusing on the caregiving of AD patients, Creasey and Jarvis (1989) interviewed 29 grandchildren, each with a grandparent suffering from AD living with them

or nearby. Their parents also completed questionnaires assessing 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. In a follow-up study, Creasey, Myers, Epperson, and Taylor (1989) had 58 children (aged 8-18 years) who had a grandparent with AD or a healthy grandparent (the control subjects) complete the Family Environment Scale, the Networks of Relationships Inventory and the Attitudes Toward Old People Scale. Rating the quality of their relationship with the grandparent, subjects with grandparents afflicted with AD rated their relationships as poorer compared with subjects who had healthy grandparents. Maternal stress was identified as a mediating influence on child/grandparent relationships. While both groups had equally positive views of elderly people in general, those whose mothers were demonstrating greater levels of burden rated their own relationships with grandparents and other older adults as poor.

In a more recent inquiry, Pruchno et al. (1995) explored negative perceptions of AD 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.

In an attempt to gain more in-depth information regarding adolescent caregiving, Beach (1994) interviewed a sample of 14 young caregivers. Each respondent was

asked a series of semi-structured questions regarding the caregiving experience.

Results indicated that the adolescents grew closer to their mothers as a result of the caregiving predicament and that they were provided opportunities to spend more time with siblings. The respondents also grew more selective of peers and acquired skills necessary in coping with aberrant behavior exhibited by the AD victim (such as using humor in a public environment). Lastly, the researcher noted that the respondents' caregiving predicaments were virtually unknown by their teachers (even though they desired more school-based support).

In a subsequent inquiry, Beach (1997) documented the positive impact caregiving had on young care providers. A sample of 20 respondents was interviewed using semi-structured, open-ended questions. The majority of adolescents in the study helped care for a grandmother with AD. Other care-receivers included aunts, uncles, and fathers. Results from the content analysis supported the investigator's prior findings via the following core categories: (a) increased sibling activity/sharing, (b) greater empathy for older adults, (c) significant mother/adolescent bonding, and (d) more stringent peer selection. Importantly, 73% of the respondents said that the caregiving situation had a positive influence on their relationships with siblings and that caregiving meant spending more time together as a family. In addition, the adolescents described themselves as more understanding of older adults in general (as a result of becoming a caregiver). They also talked of being closer to the primary caregiver of the AD victim (most often the mother), having become mom's confidant and friend. Lastly, the

respondents described themselves as more selective of their peers. Only those sensitive to the ailing AD victim were invited to the house and maintained as close friends.

Intergenerational Relationships

The literature on grandparent-grandchild relationships clusters into two primary areas of inquiry: (a) attachment to the grandparent and (b) interaction and frequency of contact with grandparents. Though intergenerational relationships take a variety of forms (i.e., child/adolescent relationships with aunts, uncles, grandparents, parents and others), the majority of research on intergenerational relationships building focuses on the grandparent/grandchild association. As such, the literature reviewed focuses on this unique relationship.

Attachment to Grandparent

A number of studies have concentrated on the level of attachment to grandparents (distinguishing between maternal and paternal grandparents) and differences between adolescent relationships with their grandmothers versus grandfathers (Charlin & Furstenberg, 1986; Kivett, 1991; Tinsley & Parke, 1984). In a study of 142 college age students, perceptions of relationships with grandmothers were compared to relational perceptions of grandfathers (Creasey & Koblewski, 1991). Using the Network of Relationships Inventory, results indicated that grandparents were not viewed as significant sources of intimacy and they were not identified as sources of aid. Nevertheless, grandparents were still rated as important in terms of attachment figures. Additionally, granddaughters reported significantly closer relationships with their grandparents as

compared to their counterparts (grandsons). In a similar study of grandparent attachment (Roberto & Stroes, 1992), 142 college-aged students completed questionnaires assessing the frequency of activities with grandparents, relationship solidarity and role conception. Interactions with grandparents were rated as infrequent, yet subjects rated their grandparents (particularly grandmothers) as important in values development. Overall, grandmothers were rated as significantly more important in value development as compared to grandfathers. Contrary to this prior research demonstrating stronger relationships with grandmothers, Oyserman, Radin, and Benn (1993) interviewed 64 two-grandparent families (with teens at home) testing the hypothesis that grandmothers have a direct influence on their grandchildren. The results, however, suggested the opposite. Namely, grandfathers were found to have a direct influence on grandchildren (i.e., nurturance and modeling, and mediation), while grandmothers demonstrated neither direct or indirect influence.

In an age-related comparative study, Mathews and Sprey (1985) found late adolescents to describe their relationships with their maternal grandmothers to be closer than their grandfathers. A sample of 132 older adolescents (college age) completed a questionnaire regarding their perceptions of grandparent relationships. Results revealed that frequency of contact and access to grandparents increased ratings of closeness to the grandmother or grandfather. Additionally, most respondents noted that their early relationships with their grandparents were sustained through adolescence. Specifically, if the respondents were close to their grandparents as young children, they tended to maintain this type of relationship during adolescence.

In an international study of grandparent attachment (Van Ranst, Verschueren, & Marcoen, 1995), 563 adolescents were interviewed using the grandparent Meaning Scale. Results indicated that adolescents generally found their grandparents to be important, but distinctions were found between early and late adolescents. Specifically, early adolescents (average age=12.5 years) assigned more meaning and importance to grandparents as compared to their older counterparts (average age=18.9 years). In general, relational-affective and caregiving meanings were more often assigned to grandmothers and teaching and narrative roles were more often assigned to grandfathers. The researchers documented no differences between granddaughters and grandsons.

Grandparent-Grandchild Interaction

The ways in which grandchildren relate or interact with their grandparents and the frequency of that interaction has been the topic of discussion in the literature (Aldous, 1995; Baranowski, 1982; Hagestad, 1985; Hartshorne & Manaster, 1982; Strom & Strom, 1992; Troll, 1985).

As early as the 1970s, investigators intended to assess adolescents' attitudes toward the aged (Ivester & King, 1977). A sample of 439 high school freshman and seniors were recruited and asked to complete the Attitudes Toward Old People questionnaire. The 32-item Likert-type scale was given to all of the subjects who rated positive and negative statements regarding the elderly. Results indicated that 12th graders and 9th graders demonstrated no significant differences with regard to negative attitudes toward the older population. In addition, frequency of contact with

grandparents had no impact on attitudes toward the older population in general. Specifically, those who had regular contact with their grandparents revealed similar attitudes toward the aged compared to their counterparts who had limited visiting opportunities. In addition, there were no differences between boys and girls with regard to attitudes toward the elderly. In another study of emotional closeness and frequency of contact with grandparents, Boon and Brussoni (1996) interviewed 171 undergraduate students (aged 16-37 years) in an attempt to evaluate their relationships with the living grandparent to which they felt closest. Not surprisingly, the subjects reported closer relationships to those with whom they had more frequent and diverse contact. Frequency of contact has also been supported in research examining differences between grandparent-grandchild relationships between rural farm and nonfarm families (King & Elder, 1995). Results indicated that grandchildren in farm families had more contact with their grandparents and rated the quality of their grandparent relationships higher than those of nonfarm families. In yet another contact inquiry, Dellman-Jenkins, Papalla, and Lopez (1987) examined voluntary interaction with grandparents among 225 adolescents aged 13-18 years. Results indicated that adolescents shared a number of recreational activities and expressed positive feelings about sharing this leisure time with their elderly grandparents.

Leisure time spent via story-telling has also been a topic of consideration regarding grandparent/grandchild interaction. Recent studies have examined the impact grandparent story-telling has on the relationship between grandparents and their grandchildren. For example, Nussbaum and Bettini (1994) asked college students to

audiotape interaction with one of their grandparents in which a grandparent told a story that captured life's meaning. Results revealed significant differences in the types of stories told by grandparents according to grandparent and grandchild gender. Cross-cultural story telling between grandmothers and granddaughters has also been examined (Wilson, 1996), with results confirming the presumption that stories are rooted in kinship responsibility to pass down the culture, identity and sense of belonging.

Adolescent Development

Empirical inquiries focusing on adolescent development typically fall into three primary categories: (a) adolescent identity exploration: family relationships and financial stress, (b) cognitive competence, and (c) predictors of adolescent risk taking. Both historical and recent research within these topic areas will be described.

Adolescent Identity Exploration: Family Relationships and Financial Stress

A number of investigators have studied the process of adolescent identity formation. In his seminal work, Erikson (1959, 1968), outlined the eight stages of development; emphasizing that adolescents experience self-doubt, confusion, disturbed thinking, conflict with authority, reduced ego strength and impulsivity while engaged in active identity exploration. More recent studies have validated these findings (Collins, 1991; Gallagher, 1996; Kidwell, Dunham, Bacho, Pastorino, & Portes, 1995; Lee, 1988).

Key to this process of identity exploration is family relationships and configurations. A wide range of researchers have described the family's impact on an

adolescent's sense of identity and ego-development (Anderson & Fleming, 1986; Bakken & Romig, 1989; Brooks-Gunn & Warren, 1989; Kramer, 1988; Papini et al., 1989; Protinsky, 1975). For example, in a 1996 study, Moser examined the feelings adolescents ($n = 132$) had toward their parents and siblings. Using self-administered questionnaires, the investigators found that emotional support of mothers and siblings was significantly more important to females as compared with their male counterparts. Additionally, discussion or communication regarding feelings occurred more often with females as compared with males (who said that their fathers told them what to do rather than generate open discussion and problem brainstorming). In another study of family configuration(s) (Larson & Lowe, 1990), 40 nonclinical, intact families were queried. Results indicated that emotional distance between parents and older adolescents was greater than the distance between parents and younger adolescents. Interestingly, a positive relationship was noted between adolescent age and spatial distance between the adolescents and each parent separately and collectively.

Given the changing nature of these family configurations, researchers have sought to identify variables that affect adolescents' attachment experiences. Interestingly, financial stress among parents has been repeatedly identified as a mediating variable in the parent-adolescent relationship (Brody et al., 1994; Conger & Elder, 1991; Isralowitz, 1989; Menaghan, Kowaleski-Jones, & Mott, 1997). As part of the Iowa Youth and Families Project (Conger et al., 1991), 400 families who lived through the Great Farm Crisis were interviewed in an attempt to examine what, if any, impact financial stress had on childhood development. Results indicated that financial stress or

hardship increased the risk of emotional problems among parents, which eventually resulted in family conflict and increased the risk of adolescent adjustment problems.

Financial hardship has also been studied with regard to level of parental employment and adolescent stress (Menaghan et al., 1997). As part of the 1979 National Longitudinal Survey of Youth, data on academic problems, family cognitive stimulation, parental structuring, and family employment stressors were gathered. Results revealed that poor quality of parental employment had negative effects on the level of cognitive stimulation and maternal warmth received by children and early adolescents. In a similar study, Conger, Xiaojia, Elder, Lorenz, and Simons (1994) interviewed 378 early adolescents from two-parent families. The investigators found financial or economic pressure to be positively associated with parental depression, hostility, marital conflict, and conflicts between parents and adolescents regarding money. These hostile exchanges were subsequently predictive of emotional and behavioral problems exhibited by adolescents.

Not surprisingly, the vast majority of financial pressure studies have concentrated on Anglo populations. However, one study of African-American families upheld the findings demonstrated in the predominantly Anglo studies. Brody et al. (1994) interviewed and observed 90 two-parent African-American families examining the impact parental financial resources had on adolescent academic competence and socio-emotional adjustment. Financial resources were significantly associated with parental depression and childrearing conflict; disruptions in parental co-caregiving ultimately

interfered with the development of the adolescent's self-regulation which influenced his/her academic competence and socioemotional adjustment.

Cognitive Competence

In an effort to further understand the effects of parental-adolescent attachment, researchers have studied predictors of cognitive competence and the impact parental relationships have on the intellectual development of adolescents (Fabes, 1987; Fortosis & Garland, 1990; Mann, Harmoni, & Power, 1989; Manning, 1988). For example, Majoribanks (1996) interviewed 800 adolescents and their parents in an effort to examine the family learning environment. Results demonstrated that a more attached parenting style coupled with higher parental aspirations were predictive of greater cognitive performance by adolescents.

Other research findings have demonstrated that a more "authoritative" parenting style is correlated with better scholastic performance by adolescents (Anderson, 1992). For example, in a study of 120 families with a first-born child between the ages of 11 and 16 (Steinberg & Elmen, 1986), interviews were conducted by the researcher which included measures of adolescent self-reliance, work orientation, resistance to peer pressure, and involvement in household responsibilities. The parent-child relationship was evaluated with regard to decision making, parental acceptance, and parental control. Results illustrated that adolescent responsibility and parenting practices defined as "authoritative" were repeatedly associated with school success.

Maternal depressive symptoms have also been linked to an adolescent's school success. In a study of 44 families, mother-daughter dyads from single parent versus

two parent households were examined (Silverberg, Marczak, & Gondoli, 1996).

Results from questionnaire data indicated that only in the single mother-daughter dyads did maternal stress play a significant role in the adolescent daughters educational expectations.

Predictors of Adolescent Risk Taking

A diverse group of researchers have examined the inclination of adolescent subgroups who engage in (or who are likely to engage in) risky behaviors. These behaviors include, but are not limited to, early or risky sexual behavior, drug and alcohol use, lack of proper nutrition and exercise, depression, and suicide (Hechinger, 1992).

Findings from the National Longitudinal Study on Adolescent Health (a sample of 12,118 adolescents) showed that parent-adolescent connectedness is protective of a number of health risk behaviors (i.e., emotional health, violence, substance abuse, and sexuality). Other smaller-scale studies on adolescent risk taking support these findings. For example, Metzler, Noell, Biglan, Ary, and Smolkowski (1994) examined the impact parental monitoring had on risky sexual behavior among adolescents. Findings showed that poor parental monitoring and coercive parent-child interactions resulted in the adolescent choosing deviant peers. Importantly, the results suggested that less availability of parental figures resulted in risky sexual behavior by the adolescent. Not surprisingly, this early, risky sexual behavior has been associated with yet other potentially health-endangering behaviors. Orr, Beiter, and Ingersoll (1991) interviewed 1,504 adolescents and found that nonvirginal boys and girls were significantly more

likely to engage in other risky behaviors such as marijuana and drug use, involvement in delinquent activities, and suicide attempts.

Subsequent research has supported the notion that poor family communication and lack of a family confidant results in more harmful behaviors engaged by the adolescent. In a study of hospital emergency department admits, Tulloch, Blizzard, and Pinkus (1997) found that young emergency department admits had significantly fewer family confidants as compared to controls. Additionally, compared with the age-matched controls, subjects described their communication with family members as significantly less fulfilling.

The use/abuse of alcohol and drugs by adolescents has also been a specific harmful behavior warranting topic discussion (Coupey, 1997; Fishman, Bruner, & Agder, 1997; Lifrak, McKay, Rosatin, Alterman, & O'Brien, 1997). Recent research reveals that adolescents from families with less education engage in more addictive behaviors (Petridou et al., 1997) and that parental "previewing" of upcoming risk situations may alleviate or reduce an adolescent's proclivity toward these precarious behaviors (Trad, 1994). Substance abuse has also been linked to depression among adolescents (Whitmore et al., 1997). Unfortunately, the vast majority of adolescent substance abusers go untreated (Ungemack, Hartwell, & Barbor, 1997).

Finally, the literature reveals that the parent-adolescent relationship is instrumental in an adolescent's inclination toward depression and suicidal tendencies (Besseghini, 1997; Griffiths, Farley, & Fraser, 1986; Ivarsson & Gillberg, 1997; Porter, Fein, & Ginsburg, 1997). For example, in an inquiry of gender differences and

depressive symptoms, investigators tracked 387 adolescents and their mothers (Reinherz et al., 1990). Using the Children's Depression Inventory and other inventory data, the researchers found that adolescents with higher depression scores had mothers who exhibited greater depressive symptomology. Both boys and girls in the high depressive group demonstrated sad affect, withdrawal, antisocial behaviors, and substance abuse. In terms of suicide, Pillay and Wassenaar (1997), studied 30 adolescents who attempted suicide and found that 78% of them reported conflict with their parents just prior to the suicidal event. Compared to matched controls, the study group reported significantly more family conflict and greater dissatisfaction with their family's functioning.

Summary

The literature reviewed clearly demonstrates the impact AD has on the entire family. The literature is abundant with information regarding the caregiving experiences of spouses and adult children. Given the particular competing responsibilities placed on adult child caregivers, it is not surprising that they experience high levels of stress. Nor is it a surprise that their children (most often preadolescents or adolescents) have been impacted by the caregiving predicament. However, the extent to which parental caregiving stress impacts the adolescent has been overlooked. Specifically, how do adolescents view their parents' caregiving experiences in relationship to their own? How much of the parents' stress is absorbed by the adolescent?

While at times contradictory, the literature described supports the notion that grandparents are generally important attachment figures to adolescents and that young

adults gain much through their interaction with these elders. Unfortunately, there is a paucity of research describing how the diagnosis of AD affects these interactions between grandparents and their adolescent grandchildren. For example, how do adolescents handle and feel about interactive situations in which the grandparent becomes angry or hostile? How does the adolescent manage a grandparent who cannot remember significant events in the adolescent's life or special moments previously shared?

The literature described also validates the fact that most studies on all types of caregivers have been quantitative in nature. In fact, of the four studies done on adolescent caregivers, only two used qualitative methods. While quantitative inquiries provide needed information, they do not allow for "thick description" in terms of experiences. In this case, when allowed an opportunity for open sharing, how does the adolescent describe his/her own caregiving experience?

The author's previous studies (Beach, 1994, 1997) have elicited interesting information from caregiving adolescents via qualitative designs. However, this prior research was done on older adolescents (average sample ages = 19 years and 18 years) and included children, grandchildren, and nieces and nephews of AD victims. Such stratified samples did not allow for detailed analysis of the impact of AD disease on the grandparent-grandchild relationship and the older samples did not provide information on younger caregiving adolescents. Moreover, the study questions in the previous inquiries focused on issues such as death and dying, social support, and positive caregiving attributes. While interesting, there are still many unanswered questions regarding the child's caregiving experience. In particular, what is it like to live with an

AD-afflicted grandparent? How is parental attention impacted by the caregiving environment? What type of historical information regarding the grandparent/grandchild relationship provides insight into the caregiving picture? In short, what happens to the young adolescent in the caregiving context?

Finally, the examined developmental literature supports the fact that parental stressors and an absence of parental involvement may have a negative impact on adolescents. It is clear that caring for a demented elder may cause a parent significant emotional and monetary stress, thus necessitating periodical disconnectedness from the adolescent. In turn, the adolescent may experience detrimental outcomes in terms of identity development and proclivity toward risky behaviors. Fortunately, the proposed study may provide much needed information from which to plan interventions for these individuals, thereby minimizing the negative impact on both the caregiving adolescent's short and long-term development.

CHAPTER III

METHODS

Qualitative studies focus on naturally-occurring events in natural settings such that a description of “real life” is obtained. Qualitative data are particularly well-suited for locating meaning as the emphasis is on individuals’ lived experiences (van Manen, 1977; Miles & Huberman, 1994). A qualitative methodology, using aspects of grounded theory, was chosen to ascertain adolescents’ lived experiences of caregiving. The structure for the grounded theorist lies in symbolic interactionism (Blumer, 1969; Mead, 1964). Essentially, the investigator tries to make sense of the symbolic meaning that gestures, clothes, words, and so forth have for people as they interact with each other. Importantly, the grounded theorist attempts to construct what interactants see as their social reality and decides that reconstructed realities are relevant if the individuals involved report that they are (Fawcett, 1991).

The following chapter describes the study design, data collection, sampling, and analysis procedures, guidelines for ensuring rigor of the data, and protection of respondents.

Study Design

This was a nonexperimental study incorporating features of grounded theory methodology (Glaser, 1978). This methodology was selected because it was useful in

ascertaining informants' perceptions of experiences while limiting opportunities for the introduction of preconceived hypotheses. Developed in the early 1960s (Glaser & Strauss, 1965, 1968), this method was first used during a field observational study of medical staff members handling of dying patients.

As noted by Stern (1994), grounded theory is just one of the interpretive methods of inquiry sharing the common philosophy of phenomenology (methods which describe the world of the person or persons under study), and as such, incorporating or triangulating interpretive methods might not be “heresy” (p. 214). Rather, triangulation may be an effort to better understand the data and lead to the development of an end product of higher quality and use (Stern, 1994). Therefore, to better understand the world of adolescent caregivers and to develop a data analysis of higher quality, a triangulated, qualitative study was employed. Aspects of grounded theory and ethnography were employed.

Respondents

A sample of 10 respondents was used for the study. To be included, respondents had to be between the ages of 11 and 18 and the grandchild of an Alzheimer's or Alzheimer's Type Dementia (ATD) victim living with his/her immediate family. To be considered an adolescent “caregiver,” respondents were directly responsible for at least one caregiving activity per day (i.e., bathing, providing respite care, grooming, transporting from home to the community). In addition, the grandparent must have had a formal diagnosis of AD from a physician and characterized as an early to middle stage dementia patient (i.e., far enough along in the disease process to require

assistance with activities of daily living where confusion, word loss, and disorientation to time and space were evident). Study participants were recruited via the local chapter of the Alzheimer's Association and the San Diego Alzheimer's Disease Research Center. Promoting confidentiality of all families, potential respondents were notified of the study by support group leaders and staff members and instructed to contact the investigator if interested in participating.

The demographic profile of respondents in this study showed the group to be mostly male (males, $n = 6$; females, $n = 4$) with an average age of 13.5 years (range 11 years-18 years). Seven of the participants were Anglo American; three were Hispanic. Three of the respondents had completed the sixth grade; 2 the eighth grade, 4 the 9th grade, and 1 had finished high school. All respondents were responsible for at least two caregiving tasks per day and all had at least one sibling (see Table 1).

Data Collection

A semi-structured interview guide consisting of open-ended questions and probes was designed (see Appendix A). Taking into consideration key elements of the ethnographic interview (Spradley, 1979), grand tour (e.g., "tell me about your grandparent's illness . . . "), descriptive (e.g., "what is it like to live with your grandparent?"), and structural (e.g., "what kinds of care do you help with?"), questions were integrated throughout the interview. More specific questioning and probing strategies were also designed to explore perceptions of these adolescents with regard to caregiving experiences that were both rewarding and not rewarding. Informed consent was obtained prior to commencement of all interviews (see Appendix B). Basic

Table 1

Respondent Profile

Category	<i>n</i>
Ethnicity	
Anglo-American	7
Hispanic	3
Gender	
Male	6
Female	4
Education	
6 th grade	3
8 th grade	2
9 th grade	4
10 th grade	1
Caregiving tasks per day	
1-2 tasks	1
3-4 tasks	3
5-6 tasks	3
7-8 tasks	2
More than 8 tasks	1
Sibling(s)	
Yes	10
No	0

Note. Average age = 13.5 years.

demographic data on each respondent was also collected; age, gender, ethnicity; grade last completed, number of siblings, and average number of caregiving tasks responsible for were recorded (Appendix C).

Data Analysis

All interviews were audio recorded, transcribed verbatim and analyzed using a two-tier system incorporating aspects of content analysis methodology (Glaser, 1978). First, open coding of the data was conducted. This phase of the analysis involved coding or extracting statements that each adolescent made that described aspects of caregiving experiences. The following three questions were asked as the coding took place: (a) what is the data a study of? (b) what category does each described incident indicate? and (c) what is actually happening in the data? Keeping these questions in mind, each transcribed data segment was reviewed and words and phrases that capture the meaning of the sentence or paragraph were assigned to each segment of the text. The content of the responses were constantly compared across interviews in order to identify core categories. Second, selective coding of the data was generated. Using the core variables as a guide, examination of the data for conditions and consequences directly related to the primary categories were coded and further evaluated for similarities and differences across interviews. The coding continued until theoretical saturation was reached. To be considered a primary category, the theme must have evidenced itself across the majority of interviews ($n = 6$). The primary core category emerging at the end of the open coding process was “Challenging the Continuum of Change” and

included the following subcategories: (a) A Missing Voice, (b) The Changing Family, (c) Coping, and (d) Reaching Out.

Dependability/Transferability

A number of methodologists have outlined methods for ensuring the transferability and dependability of data gathered using qualitative methods. Issues of quality control were addressed using a technique previously described (Smith & Robbins, 1984). Specifically, all interviews were conducted by one person (the primary investigator). Consistent with internal validity requirements outlined by Connelly and Clandinin (1990), a subsample of the participants ($n = 4$) were recontacted upon the completion of all interviews. They were asked to read an age-appropriate summary of the research findings (from all 10 interviews) and comment on the accuracy of the analysis (see Appendix D). Lastly, adhering to Firestone's (1993) "case to case" transfer issues, two colleagues independent of the study, but who work with young caregivers, were asked to comment on the respondents' reported circumstances. The Children's Programs Director at the local Alzheimer's Association and a Gerontological Social Worker who counsels families at the time of diagnosis and beyond were asked for their feedback. In short, were the results from this study similar to the issues raised by the adolescents with whom they work?

Protection of Respondents

To ensure respondent confidentiality, the investigator did not make unsolicited contact with potential study respondents. Rather, potential respondents were notified of

the study via staff members at both the Alzheimer's Association and at the San Diego Alzheimer's Disease Family Research Center at the University of California, San Diego. Before the interviews began, all respondents were notified that the study was completely voluntary and that their decision to participate would not affect their family's treatment at the Alzheimer's Disease Family Research Center in any way. In addition, if a respondent declined having his/her interview taped, he/she could still participate in the study.

Names were not used on any of the transcribed interviews; each respondent was assigned a number for identification purposes. When the data were written in manuscript form, fictional names were substituted for respondents' real names. Given the emotional nature of this subject, any respondent who might have become upset during the interview could terminate the interview altogether or reschedule it for another time (if willing). A list of referrals for additional assistance was also provided. However, because the investigator has had prior experience interviewing adolescents about this sensitive issue, she provided a caring and sensitive interview environment, thus minimizing potential for traumatic emotional reactions (no additional referrals were warranted). Finally, all interview tapes and transcribed interviews were placed in a locked file cabinet and will remain there for a period of 5 years. They are available only to the investigator and her faculty dissertation committee.

Summary

As Miles and Huberman (1994) noted, qualitative methods allow for the "thick description" of human experiences. Due to the lack of qualitative studies on caregivers

in the literature (and particularly of adolescent caregivers), a descriptive, qualitative study was particularly useful in describing the subjective experiences of adolescent care providers.

First, while much is known about spousal and adult child caregivers, the literature is scant with empirical data on adolescent caregivers. Given the vulnerable nature of adolescent development, this gap in caregiving knowledge needed to be addressed. A qualitative study of this type was quite useful in documenting the developmental experiences of this population. Second, the value of the grandparent-grandchild relationship has been repeatedly demonstrated in prior inquiries. However, the extent to which AD and adolescent caregiving responsibility affects this relationship is unknown. This study sought to understand this dynamic.

In sum, the current study used the above outlined qualitative design to document the experiences of 10 adolescent respondents. Their stories were compared and core categories and experiences were generated. The generated data will be used to help researchers, policymakers and practitioners better understand the plight of young care providers.

CHAPTER IV

RESULTS

“Challenging the Continuum of Change” emerged as the core category of the study and represented the dilemmas adolescents confronted within the caregiving environment. Specifically, each stage of the caregiving process encountered by the adolescent was met with resistance prior to acceptance; each resistance/acceptance juncture was intricately woven in the caregiving context. This challenging process consisted of four interrelated sub-categories: (a) A Missing Voice, (b) The Changing Family, (c) Coping, and (d) Reaching Out (see Figure 1) and all of these subcategories involved a number of underlying conditions.

First, the conditions falling under the rubric of a “A Missing Voice” comprised: (a) Recognizing the Difference; (b) She’s There, She’s Not There; and (c) Reversal of Blame. Second, the subcategory, “The Changing Family,” incorporated the following underlying conditions: (a) Increased Family Intimacy; (b) Loss of Sibling Trust/Sibling Inequality; (c) Parental Conflict, and (d) Accepting the Changes. Next, the category defined as “Coping” involved the following conditions: (a) Holding Back Frustrations and (b) Self-Induced Isolation. Finally, the subcategory, “Reaching Out,” included the following underlying conditions: (a) Confiding in Friends, (b) Altered Leisure Activity, and (c) On Your Best Behavior.

Figure 1. Challenging the continuum of change.

This chapter embodies a detailed analysis of the study sample and all of the collected data. Using excerpts from the transcribed interviews, all descriptive data are discussed, giving attention to the relationships existing between and among the primary category, subcategories, and underlying conditions.

The Subcategories

Throughout the open and selective coding processes, each segment of transcribed text was assigned code words which were continually sorted into similar classes. As patterns began to emerge, four subcategories made themselves evident: (a) A Missing Voice, (b) The Changing Family, (c) Coping, and (d) Reaching Out. Each of these subcategories (and conditions within each) are detailed below.

A Missing Voice

With regard to a “Missing Voice,” respondents talked about recognizing that something was “wrong” due to a lack of communication and comprehension skills demonstrated by the victim. Specifically, repetition, forgetfulness, inappropriate use of language, and loss of humor became warning signs of something amiss with grandma or grandpa; many respondents observed previously uncharacteristic anger and shortness of temper by the victim. The adolescents also described their frustrations with the victim’s impaired short-term memory with moments of clarity rooted primarily in the long-term past. Such frustrations reached even further due to the victims’ repetitive questioning, and suspicious and often paranoid queries. In sum, this compilation of frustrations led to a deterioration in the grandparent/grandchild relationship (as

perceived by the adolescent). In specific terms, the lack of connection or by-product of the disease was particularly difficult for the previously “connected” grandparent/adolescent pairs. To further illustrate, some respondents noted blaming behavior initiated by the victim who was not really “there”; feelings of guilt, having to repeatedly proclaim their love for the victim, and even victim-initiated physical violence were all well within the caregiving context.

A “Missing Voice,” used to describe the victim of Alzheimer’s disease, involved three underlying conditions: (a) Recognizing the Difference, (b) She’s There, She’s Not There, and (c) Reversal of Blame. As noted by Figure 2, “Recognizing the Difference” was the first step in the change process. Symptoms such as lack of communication skills, forgetfulness, inappropriate use of language, loss of humor, repetitive queries, and hostile/angry behavior exhibited by the AD victim comprised this phase of adolescent recognition. Upon learning that grandma or grandpa actually had AD, the remaining two conditions became increasingly pivotal to the adolescents’ experiences. Specifically, “She’s There, She’s Not There” and “Reversal of Blame” were central to the respondents’ everyday relationships with the victims. Symptoms such as impaired short-term memory, clarity linked to the long-term past, nonrelevant contextual emotions, suspicious/paranoid behavior, repetition, and loss of relational support affected these respondents across their interactions with the victim. Moreover, sensing guilt, feeling blamed, and having to repeatedly proclaim their love for the victim significantly impacted these respondents (see Figure 2).

Figure 2. Challenging the continuum of change: A missing voice.

The above mentioned conditions and behavioral outcomes served to reconfirm the adolescents' notion of "Recognizing the Difference." In short, these themes entailed an on-going system of confirmation. The following narrative details each of the conditions included in "A Missing Voice." Evidence and examples are provided via excerpts from the respondents' interviews.

Recognizing the Difference

Recognizing the difference defined the junctures in which the adolescents noticed significant changes/problems with grandma or grandpa's behavior. A number of respondents talked about recognizing that something was "wrong" due to a lack of communication and comprehension skills demonstrated by the victim. As evident from the following comments, repetition, forgetfulness, inappropriate use of language, and loss of humor became warning signs of something "awry." Moreover, a number of respondents noted the development of anger and uncharacteristic shortness of temper:

Mainly, its like her communication skills. She really wasn't able to talk too well. It's like her sentences are broken up and she was just saying like little fragments. At first I thought maybe it's because she was around kids all the time cause she used to baby-sit cause that was before they diagnosed it, like that. I always thought it was because of that but really I guess it was Alzheimer's already starting to affect her and so that was the main thing and then there's like other things like she lost her sense of humor and she didn't understand things that she would have in the past. Um, I don't know, she used to be a very talkative person and she really wasn't anymore, she was losing it. Respondent #4, lines 9-18)

She was always forgetting stuff. She always asked me a question more than once. Just things like that. (Respondent #10, lines 12-13)

Um, well, she was kind of like in a sweet, like dumb stage for like five years. The past three years, or something, she's in like kind of like mean like real

angry all the time, like staring, really short temper, stuff like that. (Respondent #2, lines 18-20)

The temper kept on getting shorter and shorter and it would be like, if I dropped a dish, my sister would drop a dish that would break, he would get mad. That's how short his temper was. (Respondent #9, line 43-45)

Compounding the anger phase, one respondent described outbursts of hostility in conjunction with alcoholic behavior. The "sundowner" conduct (drinking primarily after sunset) by the victim led to nightly confrontations with the primary caregiver. Such confrontations did not go unnoticed by the respondent

Um, my mom and I try to stay in different rooms and she [grandma] cries like every night and my mom will, like, she'll say, and my mom will say you've had enough and she'll say no I want more and stuff. One time she threw a wine bottle on the floor but, it didn't break. (Respondent #8, lines 20-23)

She's There, She's Not There

"She's There, She's Not There" involved the respondent's reconciliation of grandma or grandpa's loss of mental capabilities despite the fact that his/her physical makeup remained unchanged.

Respondents repeatedly discussed a lack of understanding on the victim's part. In particular, they described their loved one's impaired short-term memory with moments of clarity intricately woven in the long-term past. The respondents also described their frustrations with repetitive questioning, suspicious and often paranoid queries made by the victim. Finally, these respondents spoke about the lack of support as an inevitable by-product of the disease. For those who had a close relationship with their family member prior to the illness, this lack of connection was particularly painful. The following excerpts detail these findings

Um, she still smiles all the time. She even smiles when she cries sometimes. She likes to watch shows. We call them Barney shows. Its like these 50 year old movies. It's like guys singing opera and stuff, and then she like sometimes if it's a sad song, she smiles while she's crying. I don't get it. (Respondent #1, lines 151-155)

She wouldn't remember any of the memories, she would go back to her childhood instead of anything else, she would remember what she did in the third grade but she couldn't remember what she did like ten minutes ago or last year. (Respondent #3, lines 137-140)

She doesn't know, like every single minute you have to keep telling her. She'll say like when am I leaving to go visit my brother. And a few minutes later, when am I leaving to go visit my brother, and a few minutes later she'll just keep repeating the same thing over and over and over. It's really annoying. Or she'll like, when she went to go up to Lake Arrowhead, her house up there, cause she never lives up there that much, and my uncle took care of her up there. She wanted to bring down a box and she forgot it and she said where's my box, I brought this box. Where is all my stuff? You're keeping it from me. My mom would say no I'm not, I don't even know what box you're talking about. Then my uncle called later and said that she left it up there and should I mail it down, and my mom said no, just forget it. But she would always say, where's that box I brought down? I had a box of stuff you're keeping from me. You're lying. I would tell her I don't know what you are talking about. (Respondent #8, lines 378-391)

She was a very supportive Grandmother. Like anything that I wanted to do she was always there for me. You know? Like she would always go . . . she would always be there to cheer me on or help me if I needed help. And like I miss that sometimes because she's there, but I know she's not there. (Respondent #4, lines 176-182)

Reversal of Blame

“Reversal of Blame” centered on the adolescents’ feelings of being blamed for circumstances beyond their control. Related to the condition, “She’s There, She’s Not There,” the adolescents noted blaming behavior initiated by the victim who was not really “there.” In particular, they described their feelings of guilt, having the victim elicit such responses (due, in part, to the adolescents communicated need for space).

They spoke about having to repeatedly proclaim their love for the victim as it was frequently called into question. Further, one respondent talked about physical violence exhibited by the grandparent. Trying to defend himself, he was subsequently blamed for the incident and accused of fibbing. The following transcribed data sets provide voice to these findings

Well, when I'm like doing homework or something or I'm watching TV, she'll come in and start watching with me but I sort of just want to be by myself. So I sort of try to get her away but not totally, and she won't go, but I didn't say it in words like will you go, but she did and then she started crying. She cries a lot. When I'm in there, she'll come in and I'll kiss her good night and I always say good night to her and then she'll say you don't love me anymore. So I'll say I love you and she says no you don't and she'll go off crying. She does that a whole lot. I feel bad. It makes me feel like I act like I don't love her but I know I do. (Respondent #8, lines 334-342)

Um, she likes slaps a lot. . . . But and then you like block her slaps, she gets like little bumps on her hands and then she goes and tells everyone that you did that, like I did that to her. (Respondent #2, lines 29; 35-39)

The Changing Family

The "Changing Family" described the flux in the familial system as a result of the AD victim living in the home (Figure 3). Interestingly, both positive and negative outcomes of the caregiving experience were observed.

On a positive note, respondents commented on feeling closer to the caregiving parent, spending more time with siblings, and bonding with other family members. Counter to these findings, a number of negative strategies and outcomes were also outlined: making step-wise transitions, dealing with the victim becoming the center of family activity, antagonizing the victim, and making unsuccessful nursing home placements were all delicate steps taken in the caregiving process. Not surprisingly,

Figure 3. Challenging the continuum of change: The changing family.

family tension became a cornerstone of this caregiving context; inequitable distribution of caregiving tasks (and subsequent stress) between siblings and parental conflict were key features of such tenuous circumstances. However difficult, such tension compelled these adolescents to accept changes in their lives as a result of the new living arrangement. To deal with their repeatedly noted invasion of space, they created coping distance for themselves inside and outside of the home context and reluctantly placed their needs second to the victim's demands.

As previously noted, the "Changing Family" demonstrated one positive and three negative conditions: (a) Increased Family Intimacy (positive condition); (b) Getting Used to It (negative condition), (c) Loss of Sibling Trust/Sibling Inequality (negative condition), and (d) Parental Conflict (negative condition). As noted by Figure 3, "Increased Family Intimacy" was a positive consequence of the caregiving predicament. Feeling closer to the caregiving parent, spending more time with siblings, nonverbal bonding with family members, and retrospective intimacy were all noted as positive ramifications. On the contrary, "Getting Used to It" involved a number of negative strategies and outcomes. Making step-wise transitions, dealing with the victim becoming the center of family activity, antagonizing the victim, and making unsuccessful nursing home placements were all tactics outlined by these adolescents. "Loss of Sibling Trust/Sibling Inequality" was also noted as a negative consequence of the caregiving situation. Specifically, inequitable distribution of caregiving tasks, interference with school homework, having a sibling who "tunes out" the environment, and lack of understanding by younger siblings contributed to the

deterioration of the sibling relationship. The final negative condition, “Parental Conflict,” included problems created by long distance caregiving, the adolescent’s defense of mom, antagonizing behavior by the respondents, and physical violence initiated by the victim of AD. The following sketch provides analyses of these conditions, utilizing the respondents’ voices as examples of each.

Increased Family Intimacy

“Increased Family Intimacy” involved the adolescents feelings of greater intimacy with family members as a result of the caregiving predicament.

Noting a more positive trajectory, several respondents mentioned feeling closer to the primary caregiver, the noncaregiving parent, and other family members (such as siblings) as a result of the victim’s illness. As evident from the excerpts below, adolescents talked about seeing their noncaregiving parents and siblings more often, while collaborating more with the caregiving parent to make the home situation “workable.” Others described becoming closer with their siblings via nonverbal communication strategies used to cope with the victim’s “embarrassing” behaviors. Finally, one respondent noted getting closer to the grandparent retrospectively. Specifically, the victim engaged in a journal writing effort for his grandson when he was diagnosed with AD; the respondent used this journal to regain intimacy with his grandfather. The following excerpts illustrate:

I always saw my dad, but he didn’t really understand what was going on. So then we started seeing each other a lot more. My brother did a lot of things with us. Now I try to see my dad twice a month. Cause we’re up there [the mountain home] together, and then we’re down here together. He [brother]

goes to my mom's for a weekend and then I go up there and he stays down here, then I stay down here and he goes up there. (Respondent #8, lines 175-180)

Like, my mom and I are more close. . . . We have to work closer together, to make the situation better. Just things like that. (Respondent #10; lines 58-64)

It probably brought us closer together, so we would be around each other more. Do more things at home together. (Respondent #3, lines 251-254)

When she does something weird, we like, just like look at each other and kind of get along sort of, well me and my brother, just like, I don't know if she like does something, then we like just lock ourselves in our room and we don't fight as much. (Respondent #2, lines 88-92)

When I was younger, he would like, when I lived in Sacramento, he wrote a journal for me, when he found out he had Alzheimer's, he started writing a journal for me. And then every once in a while I would start to re-read it again. So I would just go back, he talked about what would happen during that day, and stuff like that. (Respondent #9, lines 147-151)

Getting Used to It

"Getting Used to It" was defined as the adolescent caregivers' methods of shift to the caregiving living environment and demanded a transition of sorts for all of the respondents.

As noted from the excerpts provided below, they talked about a progressive transition to the full-time living arrangement with their loved one. In some cases the respondents described the victim of AD spending a great deal of time in their home prior to moving in, and as such, the living arrangement approached "normal."

Conversely, others described the transition as more of a "shock," and therefore, more trying; handling their frustrations with the atypical living arrangement resulted in varying antagonistic behaviors. One case resulted in a failed nursing home placement.

The following examples exemplify these patterns:

Actually she started staying here. Like before she would stay here like a week and then go back for a week and then so it's like we kind of got used to her being here by the time she actually finally moved. (Respondent #6, lines 19-23)

It was kind of, it was tough because all of a sudden a lot of stuff would have to revolve around her. We couldn't go out cause, sometimes cause you know, leaving her alone is kind of bad. (Respondent #3, lines 50-54)

My brother and I use to really antagonize her, like when she first got here, we used to like be so frustrated with her. She asked us to do things, we would say, "like no do it yourself." Basically because we weren't really used to it and now its more like we, we are still frustrated with her but we are kind of used to it. (Respondent #6, lines 177-182)

We did try to place her in a nursing home, but we tried to put her in a nice one, not a bad one, where she would be well taken care of and my mom brought her up to one in Ramona. She started throwing food on the first meal while my mom was still there, so it was kind of embarrassing for everyone. (She brought her home.) (Respondent #3, lines 92-99)

Loss of Sibling Trust/Sibling Inequality

"Loss of Sibling Trust/Sibling Inequality" involved discomfort and resentment within the sibling relationship (especially with regard to actual caregiving responsibilities).

Several respondents talked about the inequitable distribution of caregiving tasks (and subsequent stress) between and among siblings. In particular, the female siblings said they were required to engage in more caregiving tasks than their brothers and that the predicament had less of an impact on their male counterparts. In other cases, the respondents talked about not getting to homework as a result of the victim's needs. Their siblings, however, were able to "tune out" the victim and complete their homework. While most sibling tension evidenced itself between chronologically close

siblings, such resentment was also common among respondents with significantly younger siblings. The sibling context is outlined below:

My (younger) brother doesn't really do much cause he just, he doesn't help out when my mom asks. So my mom just automatically goes to me and asks to help and I don't really say no. So whenever my mom has to go to work, I have to be the one that gives her [grandma] the pills and then I also have to take care of her dog which is Ronnie and I have to like feed her. This Friday that just happened. . . . My friend had spent the night cause school starts late (it starts at 9:15) and my mom was working and my dad was in Las Vegas so um I had to be the one that wakes her up and tells her that she needs to get ready for the center. She like says she wasn't going to go so I say like no you have to go, you have to go. She like crawls back in bed and says, no I'm not going. She thought like we weren't going to go to school and that (although I don't have a boyfriend), she said, no your just gonna invite your boyfriend over.
(Respondent #6, lines 36-52)

Well I don't think it has really affected my brother. He doesn't, I don't really know, I don't think he knows anything about it at all. Cause he's too young to understand and then um well, its like, sort of, it's a lot harder cause she gets drunk at night and mom gets really stressed out and it's a lot harder for me. He doesn't really understand. (Respondent #8, lines 64-67)

Parental Conflict

“Parental Conflict” detailed the consequences of parental tension related to caregiving. Family tension was repeatedly noted as a direct by-product of parental conflict. The respondents indicated that their parental caregiver's stress displayed itself in a myriad of ways. In particular, one adolescent discussed his parents' conflicts resulting from a long-distance caregiving predicament. The caregiving parent was caring for her husband's mother and the tension caused the respondent to “stick up” for his mom (resulting in residual resentment for his father). Another respondent detailed parental confrontations due to an increasingly antagonistic relationship with the victim (grandfather). As the respondent mentioned, his mother (the primary caregiver)

experienced a great deal of stress over this situation, which in turn, caused tension for the adolescent. Finally, the more volatile of family conflicts seemed to occur within the context of alcohol or substance abuse. In one setting, the victim of AD was using alcohol and subsequently not remembering how much she consumed in a given period. As described by the adolescent, this binge behavior led to conflict; often physical in nature. The following excerpts support these trends:

It created a lot of fights with my dad and my mom because they get mad cause he can't work down here and she'd say why can't you do more of the work? I really got mad at how much work she was having to do, and um so like my dad was in a lot of fights with her. My dad didn't really fight back though. (Respondent #3, lines 189-194)

Yeah it was kind of hard because he would pick on me the most cause I'm the oldest and my mom was getting sad because he picked on me the most. On simple things for like when we were not doing something my mom would get mad at him and then they would have a little talk and then my mom would come out and say everything was okay and stuff. (Respondent #9, lines 120-124)

Well I was in my room and I just heard the big bang cause David [stepfather] went up to tell her [AD victim] something and she sort of pushed him. I don't know why, and then my mom said don't push my loved one or something like that. And then she sort of pushed her [mom] and then she was belligerent and she fell back, so I was just hearing this big thump. (Respondent #8, lines 27-31)

Accepting the Changes

Adolescents made distinctions between acceptance in the beginning of the caregiving process (noted by the "Getting Used To It" condition) and acceptance necessary further along the caregiving path. The changing family dynamic compelled these adolescents to accept changes in their lives as a result of the new living arrangement. Not surprisingly, some accepted the changes more readily than others. As observed by the following excerpts, respondents repeatedly talked about the victim

invading their space. To deal with this intrusion, they created coping distance for themselves inside and outside of the home context. Moreover, they described having to accept the fact that their needs might be secondary to the victim's needs and sought closure to their own needs by turning to others:

Well she can't drive anymore. She fights about driving. She drinks, smokes. My uncle took her driving license away. She can't remember where she's going. She like can't drive. And she, she doesn't really have any friends that she can go out with anymore. So she's always around the house. (Respondent #8, lines 147-150)

It's okay, I mean I don't really go around her, so we don't get in that many fights anymore. I mean when I first moved here, she was, I mean, she was really nice and stuff, but then staying here so long, now it's kind of different. (Respondent #1, lines 19-22)

My mom's been stressed out more, she seems like she's stressed out more, but I've gotten used to it cause this is who she is now. It's been like this for two years. At first it's like, she was stressed out about everything and didn't want to take us places and drive us when we wanted to go to the mall or movies. Now it's like I've gotten used to it and I've learned to depend on my friends to drive and stuff. (Respondent #6, lines 131-138)

Coping

The subcategory, "Coping," comprised the principal ways in which the respondents managed the caregiving situation on an on-going basis. The conditions within this subtheme included: (a) Holding Back Frustrations, (b) Accepting the Changes, and (c) Self-Induced Isolation.

As delineated by Figure 4, "Accepting the Changes" involved an invasion of the adolescents' space, creating more coping distance, and feeling the stress experienced by their mothers. The second condition, "Holding Back the Frustrations," comprised feeling worried about mom (most often the primary caregiver), feeling that

Figure 4. Challenging the continuum of change: Coping.

communication outcomes were futile, and the expressed need for space to repress feelings. The final condition, “Self-Induced Isolation,” embodied isolation within and outside the home context, therapeutic fibbing, and nonassertive communication.

All of these conditions were aligned in a step-wise progression of coping strategies. Specifically, the adolescents experienced a variety of emotions first (Accepting the Changes) which led to a number of behavioral outcomes “Holding Back the Frustrations” coupled with “Self-Induced Isolation” (see Figure 4). Specifically, the respondents noted how they held back frustrations, accepted changes in their lives, and isolated themselves for peace (and sometimes, protection). Interestingly, they spoke openly about how hard the caregiving predicament was on their mothers; internalizing their mother’s stress led to their own repression of frustrations and feelings. They further rationalized this repressive behavior as expressing their own feelings was pointless. In short, rather than risk a possible confrontation, they chose to create distance from grandma or grandpa in the home environment and/or leave the home altogether.

The following section provides a descriptive analysis of these coping strategies. Borrowing from the respondents transcribed interviews, examples of each strategy are provided.

Holding Back Frustrations

“Holding Back Frustrations” was defined as the tendency for these adolescents to repress their feelings regarding the caregiving situation; the ability to “hold back” or repress one’s feelings resulted from a myriad of behavioral antecedents.

The respondents spoke openly about how hard the caregiving predicament was on their mothers. Viewing the stress their mothers experienced as caregivers motivated these adolescents to “hold back” their own feelings regarding the caregiving crisis. In addition, they talked about the end result of expressing one’s feelings as futile, and as such, repressed concerns and frustrations on a regular basis. Interestingly, a few of the respondents rationalized this repressive behavior in terms of an empathy model. Referring to them “as people too,” they pointed to the personhood and integrity of the victim. More commonly, however, the respondents talked about staying away from grandma or grandpa in order to successfully repress or hide feelings of anger and frustration:

There’s nothing I can really do cause my mom, my mom does so much more then like anyone else in the family put together does. So it’s not like, like she knows how frustrated I am cause she’s frustrated 20 times more for having to do all the stuff that she does. (Respondent #6, lines 99-102)

Um, I try and learn patience and try and not get mad cause it’s not gonna help and if you get mad it makes it worse; cause there’s nothing you can do about it. (Respondent #3, lines 472-474)

I try and not be as frustrated because it’s like they don’t really know what they are doing. They are people also. My brother and I used to like tease her and we didn’t really talk to her and stuff. Like now my sister and I, like whenever my sister comes over, we’ll go and just lay our head on her lap. Now we realize that it’s not really her fault, you know, but it does get really frustrating. (Respondent #6, lines 258-264)

In a way it is, so I don’t have to see her, but it’s sad, but I do want to see my Grandmother but it’s just hard. I don’t like being around her a lot cause it’s very frustrating. It’s very frustrating and you get angry really quick if you’re around her too much, so I go to the bedroom. When I’m not around her so much. I’m not like really mad at her or whatever and not taking out my anger at her for having this disease. (Respondent #4, lines 58-63)

Self-Induced Isolation

“Self-Induced Isolation” detailed the adolescents isolating behavior used to cope with grandma or grandpa's constant presence. The respondents felt invaded in their homes and distinguished between creating space in their home environments and leaving the home to gain perspective. Unfortunately, the victims' lack of communication and comprehension skills coupled with the respondents' fears of offending him/her, led to nonassertive communication regarding needs for distance. As such, these adolescents invoked explicit measures to “get away” from the victim while in the home; others felt they had to physically leave the home to create this safe haven. The following excerpts illuminate these findings:

I don't care. I tell her that the mail came or something or ask my mom to call her sister, and then my aunt calls on the phone and talks to her for a while.
(Respondent #1, lines 180-182; 186-188)

I like leave and go in my room and turn the music on and then she'll continue asking for help and I don't. It really depends on what mood I'm in.
(Respondent #6, lines 270-272)

Well, we would have to like get out of the house a lot, we would've to go to our friends house or something cause she is here and our mom made us.
(Respondent #2, lines 66-69)

Well she tends to hang around and I don't like that, I've never really liked that. Even like if my dad was there someone like that, I don't feel like right going to my grandma and saying grandma can you go away? Because I honestly do want her to go away cause I don't like having her just sit there and you know just sit there. I want to be with my friends alone in my house. So . . . I arrange to leave. . . . So it's probably why I stay away. I don't want to get frustrated with her. I would rather not be angry with her. I would rather be just cool and calm. So I feel like staying away helps me be that way. So that way when I am around her I have more tolerance. (Respondent #4, lines 255-259; 347-351)

Reaching Out

The subcategory “Reaching Out” was used to describe the respondents’ needs and strategies used for outside involvement and validation via friends and other family members. As noted by Figure 5, this theme included the following conditions:

(a) Confiding in Friends, (b) Altered Leisure Activity, and (c) On Your Best Behavior.

First, the adolescents made pointed distinctions between trustworthy and nontrustworthy peers, noting a need to build intimacy within the peer relationship prior to confiding about the caregiving predicament (“Confiding in Friends”). Second, these respondents noted a significant change in their outside leisure activity with friends and family members. They mentioned a sense of responsibility for the victim which led to a reduction in outside activity and measured involvement when activities did take place (“Altered Leisure Activity”). Last, the adolescents who were able to engage in peer-related activity at home did so due to positive compliance behavior on the victim’s part (“On Your Best Behavior”).

In specific, “Reaching Out” described the respondents’ needs and strategies used for outside involvement and peer validation. Most of these respondents made a clear contrast between friends they could confide in and those they could not. Some of their friends were trustworthy and others were simply not close enough to be made aware of the caregiving predicament. Notably, a nurturing of intimacy needed to occur within their peer relationships prior to any divulging of information regarding the family. Reaching out also involved the extent to which these individuals could participate in leisure activities. As evident from these data, limitations in activities engaged

Figure 5. Challenging the continuum of change: Reaching out.

with friends and constraints on family activity were unmistakable. In particular, the adolescents felt responsible for the victim when the primary caregiver was unavailable, and as such, curtailed their own activities. When they did engage in outside activity, it was done so with measured involvement and “checking in” was expected behavior. Interestingly, a few described the tendency of the victim to “behave” well when friends or other guests were in the home, making inside entertaining more possible. The above specified conditions contributed to the adolescents’ successful and unsuccessful reaching out tactics. They are discussed in the following narrative with transcribed excerpts used to illustrate each relational condition.

Confiding in Friends

“Confiding in Friends” involved the precise ways in which these caregiving adolescents shared their caregiving troubles with peers.

Most of the respondents made obvious distinctions between friends they could confide in and those they could not. As observed from the following comments, they remarked that some of their friends were trustworthy and others were simply not close enough to share such confidences. These adolescents also talked about a build-up of intimacy needed in their peer relationships prior to any type of confiding behavior. Those friends who experienced a similar situation (such as having a grandparent with dementia) were described as more empathic:

Well, it depends on which one [friend]. Like some of them, some of them also have grandparents with Alzheimer’s so they like know and then some of them like aren’t really close with their families so they think its sweet and they hug her [grandma] back and all that stuff and then some of them are just like what are you doing. You know? (Respondent #6, lines 216-220)

I didn't invite as many people over. I only invited close friends that already knew who she was. You know, just a new friend of mine walking in and seeing someone who doesn't really know what they are doing, it's kind of embarrassing for me. (Respondent #3, lines 359-362)

Well, it's difficult when I have to tell them that my Grandmother has Alzheimer's. When I meet them, I can't say, oh yeah, my Grandmother has Alzheimer's. . . . I can't just jump out and say my Grandmother has Alzheimer's. It took me about a month and a half to actually tell them. (Respondent #4, lines 210-217)

Altered Leisure Activity

"Altered Leisure Activity" was defined as the extent to which these adolescent made changes in their extracurricular activities. As evident from the excerpts detailed below, alterations in "leisure" activities were classified in the following ways:

(a) limitations in activities engaged with friends and (b) constraints in family activity.

As seen from the following excerpts, these adolescents felt responsible for the victim when the primary caregiver was unavailable, and as such, their own time for activities was impacted. Concerns for their mother's feelings regarding their outside activities also affected activity schedules; respondents frequently remained at home to care for their ailing grandparents. When these adolescents did engage in outside activity, it was done so with measured involvement as "checking in" more regularly was the norm:

We wouldn't want to leave her alone. Sometimes when my parents couldn't get me to a friends house, and their friends parents couldn't pick me up, so I couldn't go to the movies or anywhere with them. (Respondent #3, lines 402-404)

I feel like I can't do that as much. Cause, I don't know, she always gets mad about stuff. . . . If my mom's home, she can take care of my grandma and then I can go out. . . . If my mom's away or something, then I have to stay home. (Respondent #10, lines 109-110;135-137)

Yeah, I was still, I would go outside, I would do a certain amount of chores that day, like four or five, then I would go out for about an hour and then check back and then go out for another hour if I'm able to and then check back, like that. (Respondent #9, lines 85-88)

On Your Best Behavior

“On Your Best Behavior” involved the adolescents’ abilities to engage in outside activities due to “better” behavior demonstrated by the victim of AD.

Due to the alteration in activities noted above, some of the study participants leaned toward more leisure activity within the home context. Interestingly, a few described the tendency of the victim to “behave” well when friends or other guests were in the home (warnings issued by the primary caregiver also played a part in this more favorable behavior). As noted below, the respondents observed a sense of normalcy in the victim’s behavior; making leisure activity in the home possible

When we had company, he was very nice. He seemed like when there was someone at the house, everything went back to normal. Like something clicked and everything went back to normal. That was weird for a little while. Until I figured out like seeing people that he knows he’s seen like a while back, like it takes him back and it clicks and things go good, something like that. (Respondent #9, lines 267-271)

Usually when people come over she doesn’t really leave her room. She just like stays in there. So she doesn’t really leave. You like have to force her to come out of her room a lot of the time cause she just wants to sit in there, and it’s hot in there, like during the summer my mom will be like no you have to come outside and sit around by the pool and get some sun and all that stuff. (Respondent #6, lines 229-233)

Well, my grandma normally stays upstairs. My mom says you can’t drink while they are here. Cause it’s only at night when she starts drinking. But sometimes in the afternoon. (Respondent #8, lines 266-268)

Summary

The primary core category identified via the content analysis process was “Challenging the Continuum of Change” and illustrated the dilemmas young adolescents face when caring for a grandparent with Alzheimer’s disease. The four subcategories falling under this primary theme included (a) A Missing Voice, (b) The Changing Family, (c) Coping, and (d) Reaching Out. As outlined previously, conditions inherent within these subcategories comprised: Recognizing the Difference; She’s There, She’s Not There, Reversal of Blame, Increased Family Intimacy, Loss of Sibling Trust/Sibling Inequality, Parental Conflict, Accepting the Changes, Holding Back Frustrations, Self-Induced Isolation, Confiding in Friends, Altered Leisure Activity, and On Your Best Behavior.

With regard to a “Missing Voice,” respondents talked about recognizing that something was “wrong” due to a lack of communication and comprehension skills demonstrated by the victim. Specifically, repetition, forgetfulness, inappropriate use of language, and loss of humor became warning signs of something amiss with grandma or grandpa; many respondents observed previously uncharacteristic anger and shortness of temper by the victim. The adolescents also described their frustrations with the victim’s impaired short-term memory with moments of clarity rooted primarily in the long-term past. Such frustrations reached even further due to the victims’ repetitive questioning, and suspicious and often paranoid queries. In sum, this compilation of frustrations led to a deterioration in the grandparent/grandchild relationship (as perceived by the adolescent). Specifically, the lack of connection or by-product of the

disease was particularly difficult for the previously “connected” grandparent/adolescent pairs. To further illustrate, some respondents noted blaming behavior initiated by the victim who was not really “there”; feelings of guilt, having to repeatedly proclaim their love for the victim, and even victim-initiated physical violence were all well within the caregiving context.

The “Changing Family” described the inevitable alteration in the family network as a result of the AD victim living in the home. Interestingly, both positive and negative outcomes of the caregiving experience were observed. On a positive note, respondents commented on feeling closer to the caregiving parent, spending more time with siblings, and bonding with other family members. Counter to these findings, a number of negative strategies and outcomes were also outlined: making step-wise transitions, dealing with the victim becoming the center of family activity, antagonizing the victim, and making unsuccessful nursing home placements were all delicate steps taken in the caregiving process. Not surprisingly, family tension became a cornerstone of this caregiving context; inequitable distribution of caregiving tasks (and subsequent stress) between siblings and parental conflict were key features of such tenuous circumstances. However difficult, such tension compelled these adolescents to accept changes in their lives as a result of the new living arrangement. To deal with their repeatedly noted invasion of space, they created coping distance for themselves inside and outside of the home context and reluctantly placed their needs second to the victim’s demands.

Contending with this secondary position to grandma or grandpa fell under the rubric of “Coping.” Specifically, the respondents noted how they held back frustrations, accepted changes in their lives, and isolated themselves for peace (and sometimes, protection). Interestingly, they spoke openly about how hard the caregiving predicament was on their mothers; internalizing their mother’s stress led to their own repression of frustrations and feelings. They further rationalized this repressive behavior as expressing their own feelings was pointless. In short, rather than risk a possible confrontation, they chose to create distance from grandma or grandpa in the home environment and/or leave the home altogether.

Finally, the theme “Reaching Out” described the respondents’ needs and strategies used for outside involvement and peer validation. Most of these respondents made a clear contrast between friends they could confide in and those they could not. Some of their friends were trustworthy and others were simply not close enough to be made aware of the caregiving predicament. Notably, a nurturing of intimacy needed to occur within their peer relationships prior to any divulging of information regarding the family. Reaching out also involved the extent to which these individuals could participate in leisure activities. As evident from these data, limitations in activities engaged with friends and constraints on family activity were unmistakable. In particular, the adolescents felt responsible for the victim when the primary caregiver was unavailable, and as such, curtailed their own activities. When they did engage in outside activity, it was done so with measured involvement and “checking in” was expected behavior.

Interestingly, a few described the tendency of the victim to “behave” well when friends or other guests were in the home, making inside entertaining more possible.

In sum, these results help one to better understand the process of Alzheimer’s caregiving engaged in by the adolescent. A “Missing Voice,” “The Changing Family,” “Coping,” and “Reaching Out” all provide insight into “Challenging the Continuum of Change” and support a theory of adolescent caregiving suggesting that young adolescents “resist” before “letting go” and “accepting” at each stage of the caregiving process. The next chapter embraces these categories and conditions of change as they fit within the scientific literature on adolescent caregivers, intergenerational relationships, and adolescent development. Implications for future research and practice are discussed.

CHAPTER V

DISCUSSION

As noted in the previous chapter, several subthemes related to “Challenging the Continuum of Change” made themselves evident in this study: “A Missing Voice,” “The Changing Family,” “Coping,” and “Reaching Out” all have relationships to the empirical literature bases on adolescent development (including mental health, risk taking behavior, and cognitive competence), adolescent caregiving, and grandparent-grandchild relationships. These bodies of literature will be addressed in this chapter with specific attention given to the experiences of the study respondents. Similarities and differences with regard to prior research will be outlined and implications for future research and practice innovations will be disclosed. Specifically, what is next on the adolescent caregiving research and practice agendas, and what can we learn from these data to help plan appropriate interventions for caregiving adolescents?

Study Limitations

Before discussing the findings, a few words of caution are in order. This study was preliminary and limited in its scope of generalizability due to three primary factors. First, the sample was small, thus limiting theoretical saturation. While saturation was obtained within the sample, a larger sample size would have increased the dependability of the results. Second, while gaining the adolescent’s perspective was useful, the

experiences described here were not corroborated with any other family member's (i.e., parents, siblings, and well grandparents) perceptions. In future queries, a triangulation of family members perspectives would be helpful in confirming reported experiences. Third, this was a descriptive, "snapshot" study of caregiving adolescents. Future studies need to address the longitudinal nature of the caregiving experience. Specifically, adolescent caregivers should be followed for a greater period of time (with more in-depth interviews along the way). Information gathered in this fashion would provide more detailed data regarding the caregiving experiences of adolescents; illustrating the nature of flux inherent in the caregiving process. Last, these individuals were particularly difficult to probe and many of their responses were short, lacking detailed sharing. It is likely that this particular sample needed more time to build trust and intimacy with the investigator.

Given these limitations, this study should be regarded as a very preliminary attempt to understand how the perceptions of adolescent care providers might compare to the larger bodies of literature on adolescent development, grandparent-grandchild relationships, adolescent caregiving, and AD general. In discussing the findings of this study then, attention will be given to comparing the similarities and differences of the adolescents' experiences with the AD caregiving, grandparent-grandchild relationship, and adolescent developmental literature available.

General Symptoms

A number of respondents talked about recognizing that something was "wrong" due to a lack of communication and comprehension skills demonstrated by the victim.

Repetition, forgetfulness, inappropriate use of language, and loss of humor became warning signs of something “awry.” Respondents also noted the victim’s onset of anger and uncharacteristic shortness of temper. These junctures of recognition were consistent with the symptoms characteristically presented by victims of AD. As repeatedly noted in the epidemiologic literature, the central difficulty in providing care to victims of AD is that the disorder causes an insidious and gradual loss of an individual’s physical and mental functioning. In the early stages of the disease, an individual’s memory and complex thinking are impaired and as the disease progresses, the person’s ability to understand and respond appropriately to the world around him/her is impaired, as areas of the brain essential for impulse control and emotional stability are also damaged (Gruetzner, 1988). The symptoms recognized by the respondents also represent what medical science currently knows about symptomatic victims of AD: gradual memory loss, disorientation to time and place, decline in ability to perform routine tasks, impairment of judgment, personality changes, difficulty in learning, and loss of language skills are all within the scope of behavioral problems displayed by those with this disease (Gruetzner, 1988).

Missing in the literature, however, are data on victims of dementia who use or abuse alcohol and drugs. As evident from the current study, anger (characteristic of many AD victims), was compounded when combined with alcoholic behavior. In one case, a respondent noted that the victim’s alcoholic conduct led to nightly confrontations with the primary caregiver. Clearly, more data on this damaging combination of behaviors are warranted. In particular, what happens to the adolescent caregiver who

experiences these behaviors on a regular basis? Do these adolescents represent the typical children of alcoholics? Is sobriety an option for such victims? If so, how does the adolescent experience the “drying out” process? The literature available on alcoholic grandparents suggests that children are more likely to become alcoholics themselves if they have a grandparent with the disease; this is particularly the case for grandsons (Hartford & Grant, 1990; Perkins & Berkowitz, 1991). Moreover, alcohol consumption by the AD victim may actually accelerate the disease process (Freund & Ballinger, 1992).

These two trends have multiple implications for the caregiving adolescent. First, one must hold concern for the caregiving child more predisposed to alcoholism him/herself. Second, an acceleration of the disease may change the nature of adjustment on the adolescent’s part. A more rapid deterioration of the victims’ abilities will no doubt change the adolescent’s experience, giving him/her less time to recoup and adjust between stages of the disease. In sum, this two part paradigm needs further study; the adolescent grandchild of the demented alcoholic may require special attention.

Memory Problems

Respondents in the current study also discussed the lack of understanding on the victim’s part. In particular, they described their loved one’s impaired short-term memory and lack of support by the now-diseased grandparent. For those who had a close relationship with their grandparent prior to the illness, this lack of connection was particularly painful. Consistent with findings noted by Creasey et al. (1989), children

and adolescents whose grandparents have AD rate their relationships as poorer compared with those who have healthy grandparents.

The respondents in the current study repeatedly noted a poor relationship with the grandparent and stressed missing the previously strong connection to him/her. This lack of connection and grieving was more evident with adolescents having maternal grandmothers (rather than grandfathers) with AD. These findings serve to uphold previous empirical inquiries in which level of attachment to maternal grandparents has been explored (Charlin & Furstenberg, 1986; Kivett, 1991; Tinsley & Parke, 1984). For example, Creasey and Koblewski (1991) found that even maternal grandparents viewed as insignificant sources of intimacy were rated as important in terms of attachment figures. Moreover, Roberto and Stroes (1992) found that despite infrequent interactions, children rated their grandparents (particularly grandmothers) as important in values development. The data from the current study appear to support such findings, giving weight to the grandchild-grandparent relationship regardless of interaction frequency. In short, while the respondents in this study had very little “meaningful” interaction with the afflicted grandparent, their input was, nonetheless, important (and missed).

Grieving the Loss

These respondents appeared to continually mourn this missing connection with the victim. In prior research, the meaning and power of the relationship with the deceased grandparent has been shown to play a significant role in the adolescents' bereavement process (Fleming & Balmer, 1996; Seager & Spencer, 1996; Yates,

Fullerton, Goodrich, & Heinssen, 1989); those with better relationships had a more difficult time with their grief work (Hatter, 1996).

Additionally, the “right way” to tell a child about the impending death of a grandparent has been studied (Siegel, 1988), and dimensions of spiritual growth as a result of a grandparents’ death have been explicated (Irizarry, 1992). Missing, however, is a literature base on grieving grandchildren of AD-afflicted grandparents. Clearly, this is a unique grieving process as the victim is “here,” but “not here.” Specifically, how do adolescents grieve the loss of a grandparent who is gone in mind, but here in body? How does this journey differ from grieving the loss of grandma or grandpa due to other illnesses such as cancer, Parkinson’s disease, heart disease, and so forth? At what point in the disease process do children and adolescents accept (if at all) that grandma or grandpa will never get “better?” Finally, what type of counseling, relational work, or other interventions might help these children to “let go” of grandma or grandpa? These are all important empirical questions worthy of attention by researchers and practitioners in the fields of gerontology and adolescent development.

Positive Outcomes

As previously outlined, results from this study revealed both positive and negative caregiving outcomes for these respondents. Noting a more positive trajectory, several respondents mentioned feeling closer to the primary caregiver, the noncaregiving parent, and other family members (such as siblings) as a result of the victim’s illness. The adolescents also talked about seeing the noncaregiving parents and siblings more often, while collaborating more with the caregiving parent to make the home

situation “workable.” Interestingly, these trends have been previously identified in a study of 14 caregiving adolescents (Beach, 1994). Results from this earlier study suggested that caregiving adolescents grew closer to their mothers as a result of the caregiving predicament and that they were provided opportunities to spend more time with siblings. This particular inquiry also revealed a positive approach deemed “non-verbal bonding” in which adolescents glanced at each other for support during trying times with the victim. The current study upholds these results; respondents described becoming closer with their siblings via nonverbal communication strategies used to cope with the victim’s “embarrassing” behaviors. For example, when grandma or grandpa made funny sounds or had incontinence problems in public, the caregiving siblings might roll their eyes at each other or laugh to convey mutual support.

These more “positive” findings were further explicated in a more recent inquiry (Beach , 1997). The majority of respondents in this prior study maintained that the caregiving situation had a positive influence on their relationships with siblings. Caregiving meant spending more time together as a family and feeling closer to the primary caregiver of the AD victim (most often the mother). While these trends toward intimate growth within the family (i.e., spending more time together, feeling closer to the primary caregiver, cooperating with the primary caregiver, and nonverbal bonding) have been previously documented, the nature of “retrospective” bonding or intimacy outlined in the current study has not been formerly recognized. One respondent’s efforts to remain close to his grandparent via a journal written by the victim was unique and warrants further exploration.

Journal writing has been previously prescribed as a form of therapy in a range of contexts, but predominantly discussed from the writer's perspective (Creadick, 1985; Sinnott, 1995; Wadeson, Durkin, & Perach, 1989); the potential use by the receiver or reader of such a journal has not been explicated. In the case of adolescent caregivers, what are the positive and negative consequences of such an effort? How can the caregiving adolescent use a journal to grieve his/her loss? Can the adolescent use the journal to write his/her own letters to the victim? These features of journal writing are worthy of more investigation, the results of which could reveal interesting intervention modalities.

Negative Outcomes

The above mentioned outcomes were mostly positive in nature. Results from the current study also revealed a number of negative caregiving repercussions for the adolescent. First, getting used to the new living arrangement demanded a transition of sorts for all of these respondents. Most of them described the transition as a “shock”; handling their frustrations with the atypical living arrangement resulted in varying antagonistic behaviors. Not surprisingly, the adolescents whose mothers (or primary caregivers) were having a more difficult time with the transition, reported more difficulty themselves. As previously outlined by Creasey and Jarvis (1989) and subsequently by Creasey et al. (1989), maternal stress is often the mediating factor in the grandparent-grandchild relationship. More specifically, caregiving mothers who demonstrate higher levels of caregiving burden tend to “hand down” their stress. In short, adolescents with stressed out moms experience more caregiving burden

themselves. As evident from the current study, this pattern was unmistakable within the caregiving transition process.

This transition process also involved a great deal of sibling acrimony. Respondents in this study talked repeatedly of the inequitable distribution of caregiving tasks (and subsequent stress) between themselves and their siblings. In particular, the female siblings felt more demanded upon with regard to caregiving tasks compared to their brothers. From their perspective, the predicament had less of an impact on their male counterparts. Confirming findings in earlier study on caregiving adolescents and children (Aldridge & Becker, 1993), parents most often elect one child to serve as caregiver and other family members and siblings are happy to relinquish the role. Moreover, school and career-oriented activities and aspirations are curtailed as the role of caregiver is all-consuming. Data from the current study align with these prior findings as one child was typically chosen as the surrogate caregiver. These chosen few noted the difficulty they had completing homework and other responsibilities while their siblings appeared to be minimally impacted. The parental caregivers appeared to have inequitably “passed the torch” to one child, rather than ensure a more equal distribution of caregiving responsibilities between their daughters and sons.

Disturbingly, once this torch is passed, caregiving roles are hard to change (much less relinquish). As noted by Globerman (1995), childhood reputation tends to follow individuals into adult life. In a study of adult child caregivers, siblings “excused” from responsibility in the past appeared to be uninvolved as adults when faced with caregiving tasks. One must ask, what legacy are these adult child caregivers

passing on to their adolescent children? Such dynamics must be further examined and may be an integral part of any caregiving intervention. In short, if these caregiving parents were aware of their behavior, would they stop such inequitable role assignment? Further, how can one help the over-burdened adolescents release some of their tasks (and subsequent tension) to siblings and other family members?

Parental tension further evidenced itself as experienced by the adolescent. Respondents indicated that their parental caregiver's stress displayed itself in a myriad of ways that affected their everyday functioning. In particular, those respondents reporting more parental stress revealed greater tension and anxiety in their own lives and experienced less satisfying relationships with their grandparents. This digesting or handing down of stress has been detailed in other studies (both of caregiving and noncaregiving adolescents). For example, Creasey and Jarvis (1989) interviewed 29 grandchildren, each with a grandparent suffering from AD living with them or nearby. Results indicated that grandchildren had a poorer relationship with their grandparents if their mothers (the primary caregivers) were experiencing high levels of burden. Moreover, Creasey et al. (1989) found that maternal stress was a mediating influence on child/grandparent relationships. In particular, adolescents whose mothers were demonstrating greater levels of burden rated their own relationships with grandparents and other older adults as poor. Such stress resulted in poor family communication patterns regarding the caregiving predicament.

As previously noted, these study respondents felt repressed and anxious about expressing their feelings regarding the situation at home. Unfortunately, poor family

communication (especially between parents and adolescents) has been repeatedly marked as a sign of family dysfunction (Jackson, Bijistra, Oostra, & Bosrria, 1998; Rathunde, 1997). Specifically, poor parent-child interaction regarding ill grandparents has been proven problematic because most of these families possess few problem solving capabilities (Lund, Feinhauer, & Miller, 1985). Moreover, dysfunctional communication patterns between parent and adolescent pairs leads to depression among adolescents (Slesnick & Waldron, 1997).

Unfortunately, research demonstrates that caregiving parents will continue to experience stress associated with their caregiving responsibilities. Up to 39% of caregiving adult daughters and 25% of caregiving sons report significant distress due to their reported loss of self (Cohen et al., 1990; Skaff & Pearlin, 1992). This distress will continue to carry-over to their children, and as such, needs to be addressed. Specifically, how can stress in the primary caregiver's life be reduced? Such a reduction appears necessary in minimizing adolescent caregiver tension and anxiety; this cyclical pattern is worthy of further inquiry and possible intervention.

Acceptance

Despite the tension in their lives and resistance to the changing family system, most respondents reported having to ultimately accept changes in their families. In particular, they talked about the victims invading their space, creating coping distance for themselves inside and outside of the home context, and having to place their needs as secondary to the victims' demands.

Consistent with work by Aldridge and Becker (1993), these adolescents accepted their roles as caregivers despite neglect by other family members. These findings are worrisome as adolescents who are parented in a less attached style (as was often the case with this sample), are less likely to succeed in school (Majoribanks, 1996), and are more likely to engage in more risky behaviors such as drug and alcohol use and early or risky sexual behavior (Hechinger, 1992). In terms of future empirical inquiry, then, we must continue the dialogue with caregiving parents as well as their children. For example, what systems might serve to support the caregiving family? Is it respite care? Is it group or family counseling? The findings from this study illuminate the systemic nature of caregiving anxiety and stress and the interrelationships of each within the family. As a consequence, the entire family must be treated as the unit of analysis in any further inquiries.

Holding Back

Coping merged as a primary theme and included the principal ways in which the respondents managed the caregiving situation on a daily basis. The majority of respondents described their most popular coping technique as one of holding back or repressing their feelings regarding the caregiving predicament.

In particular, they discussed how hard it was to view their own mother's stress. In an effort to protect their parental caregivers from more tension and anxiety, they systematically held back expression of their own needs and desires with regard to this process. Interestingly, this holding back of feelings and lack of support may be critical to the development of the adolescent. As pointed out in prior research (Moser, 1996),

emotional support from mothers is significantly important to adolescent children and was clearly missing in a number of the respondents who reported their feelings as secondary to the victims; mom or dad was unavailable and they turned to others to meet their needs.

Interestingly, a few of the respondents rationalized this repressive behavior in terms of an empathy model. Referring to them “as people too,” they focused on the personhood and integrity of the victim. Such a suggestion has been delineated in earlier work by the author (Beach, 1997) in which caregiving adolescents were shown to demonstrate greater empathy for older adults as a result of the caregiving role. To maintain such empathy, however, respondents in the current study reported staying away from the victim to maintain their composure. Isolation both inside and outside of the home context were popular modes of coping and often resulted in poor (or minimal) family communication.

This isolating behavior has been previously identified as a coping strategy; more popular among older adolescents (Larson & Lowe, 1990). Contrary to these age-stratified findings, data collected from the current study show both younger and older adolescents to employ isolation as a coping device. When exploring the potential fallout from this type of coping strategy, it is important to note that poor communication resulting from isolation can result in risky behavior by the adolescent. For example, in their recent study, Tulloch et al. (1997) found that young emergency department admits had significantly fewer family confidants as compared to controls.

Additionally, compared with the age-matched controls, subjects described their communication with family members as significantly less fulfilling.

Time for Me

Coping with the situation also involved activities with friends and family. These adolescents felt responsible for the victim when the primary caregiver was unavailable, and as such, their own time for activities was impacted. Concerns for their mothers' feelings regarding their outside activities also affected activity schedules; respondents frequently remained at home to care for grandparents.

When these adolescents did engage in outside activity, it was done so with measured involvement and "checking in" was more routine. Consistent with their findings, Aldridge and Becker (1993) noted that caregiving respondents revealed a significant commitment to their caregiving role despite neglect by other family members and peer relationships, and social lives were severely restricted within the caregiving confines. While their time was restricted, respondents in the current study developed coping methods via outside or within the home activity; distinctions were made between friends they could confide in and those they could not. They described some of their friends as trustworthy, while others were simply not close enough to obtain intimate family information. Moreover, a strong relational foundation was required prior to any type of confiding behavior. Upon meeting these standards, peers were invited into the home and/or made aware of the situation when making extracurricular plans.

Such findings are congruent with work previously done on adolescent caregivers in similar situations. Specifically, Beach (1994) found that caregiving children and adolescents become more selective of their peers, inviting a favored few (sensitive to the context) into their homes. These results were further reinforced in a subsequent inquiry (Beach, 1997) in which caregiving adolescents noted a more strict process of peer selection and maintenance. Friends invited into the home were particularly empathetic to the adolescent's predicament. Akin to data presented in the current study, developing and maintaining more stringent peer selection and maintenance processes allowed these adolescents to engage in a measured amount of outside or extracurricular activity.

While only a first step in the exploratory process, these data provide interesting information regarding the adolescent caregiver-peer relationship. More information, however, is needed in this area and future investigations need to examine these associations. For example, how important are these selected peers to the caregiving adolescent? How, if at all, do peers help reduce adolescent caregiver stress? In what ways do these peers interact with the grandparent with AD? How do these peers feel about their friends's predicaments? Given the relative importance of peer relationships during this volatile time of development, the precise nature of this relationship within the caregiving context deserves greater explication.

The Noncategories

Upon completing the data analysis, it was quite obvious that a number of issues typically raised by adolescents were noticeably absent from these data. For example,

none of the respondents mentioned their own (not the victims') drug and alcohol use. Next, not one of the respondents discussed church, religion, or spiritual issues connected with the caregiving experience. Last, none of the respondents described their own sexuality and/or dating experiences as they related to outside activities or caregiving.

After working with these respondents over a 4-month period of time, a few explanations for these omissions are offered. First, this sample was significantly younger than samples used in my prior studies. This younger group appeared to withhold and most likely needed to "know" me for a longer period of time prior to sharing very sensitive information. Next, this younger sample precluded more elaboration on the questions offered. In my prior studies with older adolescents, these issues would have likely surfaced with the open ended queries provided. Conversely, this younger sample required very detailed questions on each issue of interest. In other words, if I wanted information on drug and alcohol use, sexuality, or spirituality, detailed questions on those issues should have been designed and included in the interview guide. These lessons should not be forgotten when designing future studies on younger adolescents.

Intervention Modalities/Information Dissemination

Given the nature of the caregiving influence on young adolescents, it seems appropriate that educational programs for these young people might be a natural outgrowth of this study. However "traditional" lecture or support group interventions previously used with this population have been unsuccessful and obtaining attendance at

such events has been met with formidable resistance. Therefore, the following alternative intervention modalities are suggested.

First, age-appropriate literature in the form of short books, pamphlets, and newsletters should be developed. These caregiving adolescents could read and absorb the information on their own time-lines with little threat to their confidentiality. Second, educational videos might provide user-friendly information to these adolescents via a technology with which most are quite familiar (and comfortable). Last, computer-based, on-line chat rooms and supportive services moderated by a facilitator might provide a less threatening, anonymous forum from which to learn and express feelings about the caregiving predicament. Last, information in the form of lectures, written summaries, and informational family meetings should be undertaken to inform parents of the adolescent's caregiving experiences. In short, how can these parents and families use these data to help their own caregiving children? All of these information/intervention methods are worthy of further inquiry and exploration.

Recommendations for Further Research

Data from this study of caregiving adolescents have provided interesting implications for future research and practice. The following suggestions are offered to both researchers and practitioners in the areas of gerontology and adolescent development.

First, subsequent empirical inquiries must address the longitudinal nature of the caregiving process. Studies which employ more interviews with more respondents over a greater period of time (i.e., from diagnosis to death) will more accurately display the dynamics of adolescent caregiving. Additionally, this increase in interviews would

likely build intimacy and trust between the respondent and the researcher. As a consequence, the respondent may share more information as this unique relationship deepens.

Second, more diverse respondent populations must be recruited and queried. The current sample was predominantly Anglo American and Hispanic. Though a more representative sample than most, the limited data set precluded comparisons between these ethnic subgroups and should be done so in future studies. It is quite possible that caregiving is experienced in significantly different ways by varying ethnic groups.

Third, grieving the loss of grandma or grandpa with AD must be looked at more closely. Data revealed here provided a brief glimpse into the unique mourning process and loss associated with AD. This practice needs closer scrutiny; providing meaningful comparisons to those grieving the loss of grandma or grandpa to AD versus those mourning grandparents lost to other chronic and/or terminal illnesses such as cancer, heart disease, Parkinson's disease, and stroke is necessary.

Lastly, other methods of inquiry must be considered when studying younger adolescents. These individuals were particularly difficult to probe and many of their responses were short, lacking detailed sharing. Photo-ethnography is one avenue of inquiry worthy of consideration. Having these young adults use cameras to capture the nature of their caregiving experience would likely provide topics and avenues of discussion and expression. Using this type of an "ice breaker" might lead to more fruitful discussions between the researcher and adolescent respondent. Similarly, the use of respondent diaries might also add to the potential richness of data extraction. Using daily or weekly writings provided by the respondent, questions and probes could be

formulated which may lead to more open sharing and elaboration of the adolescents' caregiving experiences. Such alternative methodologies might also have a cathartic effect on these young adolescent's, giving them avenues of expression not previously provided.

The suggestions detailed above focus on research endeavors that are descriptive in nature and are needed to bridge gaps in the available adolescent caregiving/development literature. The second pool of recommendations are less descriptive and focus on needed intervention research. First, data outlined in the current study (and others) suggest that stress and tension associated with caregiving involve the entire family. In particular, adolescent caregiver stress is significantly related to the primary adult caregiver's (mostly mom's) tension and anxiety associated with the caregiving predicament. Moreover, parental caregivers tend to choose one child to serve the role of adolescent care provider and place him/her under undue distress. As a consequence, this chosen child may be put at risk for school and other behavioral problems; interventions that focus on the entire family seem appropriate. For example, in a group session/intervention, adolescents and parents might start with some time together and have open discussions facilitated by an outside party. Next, these groups would split into parent/adolescent subgroups and receive their own tailored interventions. Parents might practice skill building regarding stress reduction and subsequently provided with opportunities to explore division of caregiving responsibilities among their children. Conversely, the adolescents would be given a safe haven (without parents or grandparents) in which to express their feelings about the caregiving situation. They would also

be provided opportunities to practice communication skills with their parents (and ill grandparents). Journal writing might also be explored. Having both caregiving parents and adolescents “journal” could prove useful in “breaking the ice” with each other and building intimacy between the parent-adolescent pairs. Lastly, the use of peer mentors in adolescent interventions is worthy of exploration. Given the importance of these relationships during adolescence, it might be useful to pair “seasoned” adolescent caregivers with those beginning the caregiving journey. Creating a forum for safety, these pairs might help each other through a very difficult time.

Summary

In sum, the data presented here have provided provocative results which have important implications for future research and practice in the arena of adolescent caregiving and AD. Given population projections and epidemiological data currently available, it is unlikely that a cure for AD will be found in the near future and adult child caregivers will continue to handle the care of their parents (asking their own children and adolescents to participate). As such, it is imperative that the above mentioned recommendations for research and practice be underscored. Practitioners, researchers, and the community at large, all have a vested interest in improving the quality of life for these young adults.

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APPENDIX A

INTERVIEW GUIDE

INTERVIEW GUIDE

CAREGIVING ADOLESCENTS

- 1) Tell me about your grandparent's illness...
How long has he/she been sick?
- 2) What is it like to live with your grandparent?
- 3) What kinds of care do you help with? How do you feel about having these caregiving responsibilities?
- 4) How, if at all, has caregiving impacted your family?
- 5) How, if at all, has caregiving affected your relationship(s) with your parents? Tell me about that...
- 6) Can you describe your relationship with your grandparent before he/she became ill?
- 7) How, if at all, has Alzheimer's changed your relationship with your grandparent? Can you tell me more about that...
- 8) How, if at all, has caring for your grandparent influenced your feelings about other older adults? Tell me about that...
- 9) How, if at all, has caregiving changed your relationships with friends?
- 10) How, if at all, has caring for your grandparent changed your activity schedule?
- 11) Is there anything else you would like to add about your caregiving experience?

APPENDIX B

CONSENT FORMS

Assent Form — Respondent

I've been invited to participate in a study of adolescent caregivers. This research is being conducted by Diane L. Beach, a doctoral student at the University of San Diego.

If I decide to participate, I will be asked some questions about caring for my grandparent. I may be interviewed up to three times and each interview will last approximately 45 minutes. The interview will include topics such as what is good and bad about caregiving, how I feel about my grandparent, and how I deal with stress. Should I become upset during the interview, I can stop the interview or reschedule it if I want to. If I need someone else to talk to, I will be given a list of professionals to contact.

I may choose whether I wish to be interviewed at the Alzheimers Association, the San Diego Alzheimer's Research Center, my home, or at another private setting. I can refuse to answer any of the questions asked or stop the interview at any time without penalty. If I decide to stop the interview, my tape will be destroyed and nobody will see or hear of it. My participation is completely voluntary and my decision to be interviewed or not will not affect my family's treatment at the Alzheimer's Disease Research Center or the Alzheimer's Association in any way.

All of my responses will be kept private; no information will be shared with my parent, grandparent or other family members. However, if I disclose that I'm being abused in any way, Diane must report this to Child Protective Services. Also, if I report any abuse of my grandparent, Diane must report this to Adult Protective Services. To ensure privacy, my name will not be used on the interview transcript. All written reports will be changed to keep my privacy (i.e., names will be changed in all written reports) and a summary of the findings will be sent to me if I wish.

If I have any questions, I can ask at this time. Should I think of other questions later, I can phone Diane Beach any time at 275-6135.

I will be given a copy of this form.

I am making a decision whether or not to participate. My participation is voluntary; my signature indicates that I have decided to participate, having read the information provided above.

Signature of Participant

Date

Signature of Investigator

Consent Form — Parent

My child has been invited to participate in a study of adolescent caregivers. This research is being conducted by Diane L. Beach, a doctoral student at the University of San Diego.

If I consent to my child's participation, I understand that he/she will be asked a series of questions regarding his/her caregiving experience. My child may be interviewed up to three times with each interview lasting approximately 45 minutes. Interview topics will include the positive and negative aspects of caregiving, how my child views his/her relationship with his/her grandparent, and how he/she copes with stress. Should my child become upset during the interview, he/she can stop the interview or reschedule it if he/she wants to. My child may also be given a list of professional referrals if necessary.

If I consent to my child's participation in the study, my child may choose whether he/she wishes to be interviewed at the Alzheimers Association, the San Diego Alzheimer's Research Center, his/her home, or at another private setting. My child can refuse to answer any of the questions asked or stop the interview at any time without penalty. If my child decides to stop the interview, his/her tape will be destroyed.

All of my child's responses will be kept confidential; no interview information will be shared with me, my parent(s) or other family members. To ensure privacy, my child's name will not be used on the interview transcript. All written reports will be changed to ensure his/her privacy (i.e., names will be changed in all written reports). If my child discloses that he/she is being abused in any way, Ms. Beach must report this to Child Protective Services. In addition, if my child reports abuse of his/her grandparent, this must be reported to Adult Protective Services.

If I have any questions, I can ask at this time. Should I think of other questions later, I can phone Diane Beach at 275-6135.

I will be given a copy of this form.

I am making a decision whether or not to consent to my child's participation. My signature indicates that I have decided to let my child participate, having read the information provided above.

Signature of Parent

Date

Signature of Investigator

APPENDIX C

DEMOGRAPHIC INFORMATION SHEET

DEMOGRAPHIC DATA

Respondent ID # _____

1. AGE _____

2. GENDER _____

3. ETHNICITY

1) CAUCASIAN

2) AFRICAN AMERICAN

3) HISPANIC

4) ASIAN/PACIFIC ISLANDER

5) NATIVE AMERICAN

6) OTHER: PLEASE LIST _____

4. GRADE LAST COMPLETED

1) 8TH GRADE

2) 9TH GRADE

3) 10TH GRADE

4) 11TH GRADE

5) 12TH GRADE

6) OTHER: PLEASE LIST _____

5. HOW MANY SIBLINGS? _____

6. HOW MANY CAREGIVING TASKS PER WEEK?

1. 1-2

2. 3-4

3. 5-6

4. 7-8

5. NONE

6. MORE THAN 8 PER WEEK

7. Relationship to Patient

APPENDIX D

SUMMARY OF FINDINGS

SUMMARY OF FINDINGS

The primary categories identified were: (a) A Missing Voice, (b) The Changing Family, (c) Coping, and (d) Reaching Out.

A Missing Voice

A number of you talked about recognizing that something was “wrong” due to a lack of communication and comprehension skills demonstrated by your loved one. Repetition, forgetfulness, inappropriate use of language, and loss of humor became warning signs of something “wrong.”

Recognizing the Difference

Mainly, its like her communication skills. She really wasn't able to talk too well. Its like her sentences are broken up and she was just saying like little fragments. At first I thought maybe its because she was around kids all the time cause she used to baby-sit cause that was before they diagnosed it, like that. I always thought it was may because of that but really I guess it was Alzheimer's already starting to affect her and so that was the main thing and then there's like other things like she lost her sense of humor and she didn't understand things that she would have in the past. Um, I don't know, she used to be a very talkative person and she really wasn't anymore, she was losing it.

She's There, She's Not There

Many of you discussed a lack of understanding on your loved one's part. In particular, you described his/her impaired short-term memory:

Um, she still smiles all the time. She even smiles when she cries sometimes. She likes to watch shows. We call them Barney shows. Its like these 50 year old movies. Its like guys singing opera and stuff, and then she like sometimes if its a sad song, she smiles while she's crying. I don't get it.

Reversal of Blame

A number of you noted blaming behavior initiated by your family member who was not really “there.” In particular, you described your feelings of guilt and talked about having to repeatedly proclaim your love:

Well, when I'm like doing homework or something or I'm watching TV, she'll come in and start watching with me but I sort of just want to be by myself. So I sort of try to get her away but not totally, and she won't go, but I didn't say it in words like will you go, but she did and then she started crying. She cries a lot. When I'm in there, she'll come in and I'll kiss her good night and I always say good night to her and then she'll say you don't love me anymore. So I'll say I love you and she says no you don't and she'll go off crying. She does that a whole lot. I feel bad. It makes me feel like I act like I don't love her but I know I do.

The Changing Family

The “Changing Family” describes the changes in your family as a result of the caregiving situation. Several of you mentioned feeling closer to your parents and other family members (such as brothers and sisters) as a result of the situation:

Increased Family Intimacy

I always saw my dad, but he didn't really understand what was going on. So then we started seeing each other a lot more. My brother did a lot of things with us. Now I try to see my dad twice a month. Cause we're up there [the mountain home] together, and then we're down here together. He [brother] goes to my mom's for a weekend and then I go up there and he stays down here, then I stay down here and he goes up there.

Like, my dad and I are more close. . . We have to work closer together, to make the situation better. Just things like that.

It probably brought us closer together, so we would be around each other more.

Getting Used to It

Getting used to it meant a transition for all of you. Some of you had a pretty easy time, but others of you had more difficulty:

Actually she started staying here. Like before she would stay here like a week and then go back for a week and then so its like we kind of got use to her being here by the time she actually finally moved.

It was kind of, it was tough because all of a sudden a lot of stuff would have to revolve around her. We couldn't go out cause, sometimes cause you know, leaving her alone is kind of bad.

Loss of Sibling Trust/Sibling Inequality

Several of you talked about the unfair distribution of caregiving tasks between yourselves and your brothers and/or sisters:

My brother doesn't really do much cause he just, he doesn't help out when my mom asks. So my mom just automatically goes to me and asks to help and I don't really say no. So whenever my mom has to go to work, I have to be the one that gives her [grandma] the pills and then I also have to take care of her dog which is olie and I have to like feed her. This Friday that just happened. . . . My friend had spent the night cause school starts late (it starts at 9:15) and my mom was working and my dad was in Las Vegas so um I had to be the one that wakes her up and tells her that she needs to get ready for the center. She like says she wasn't going to go so I say like no you have to go, you have to go. She like crawls back in bed and says, no I'm not going. She thought like we weren't going to go to school and that (although I don't have a boyfriend), she said, no your just gonna invite your boyfriend over. . . .

Well I don't think it has really affected my brother. He doesn't, I don't really know, I don't think he knows anything about it at all. Cause he's too young to understand and then um well, its like, sort of, it's a lot harder cause she gets drunk at night and mom gets really stressed out and it's a lot harder for me. He doesn't really understand.

Parental Conflict

Many of you said that your parents' stress was difficult to watch:

It created a lot of fights with my dad and my mom because they get mad cause he can't work down here and she'd say why can't you do more of the work? I really got mad at how much work she was having to do, and um so like my dad was in a lot of fights with her. My dad didn't really fight back though. . . .

Accepting the Changes

The changing family dynamic led most of you to accept changes in your lives; you talked about needing your own space:

Well she can't drive anymore. She fights about driving. She drinks, smokes. My uncle took her driving license away. She can't remember where she's going. She like can't drive. And she, she doesn't really have any friends that she can go out with anymore. So she's always around the house.

My mom, not really my dad because, he's just there. My mom's been stressed out more, she seems like she's stressed out more, but I've gotten used to it cause this is who she is now. Its been like this for two years. At first its like, she was stressed out about everything and didn't want to take us places and drive us when we wanted to go to the mall or movies. Now its like I've gotten use to it and I've learned to depend on my friends to drive and stuff.

Coping

The primary category, "Coping," included the ways in which you managed the caregiving situation on an on-going basis.

Holding Back Frustrations

Most of you spoke openly about how hard the caregiving situation was on your mothers. Viewing their stress motivated most of you to “hold back” your own feelings regarding the caregiving of grandma or grandpa:

There's nothing I can really do cause my mom, my mom does so much more then like anyone else in the family put together does. So its not like, like she knows how frustrated I am cause she's frustrated 20 times more for having to do all the stuff that she does.

Um, I try and learn patience and try and not get mad cause its not gonna help and if you get mad it makes it worse; cause there's nothing you can do about it.

Self-Induced Isolation

Many of you created ways to “get away” from your grandma or grandpa while in your home. Sometimes, you had to physically leave the home to have some space:

I don't care. I tell her that the mail came or something or ask my mom to call her sister, and then my aunt calls on the phone and talks to her for a while.

I like leave and go in my room and turn the music on and then she'll continue asking for help and I don't. It really depends on what mood I'm in.

Reaching Out

The theme “Reaching Out” was used to describe your needs and strategies used for outside involvement with friends and other family members.

Confiding in Friends

Most of you made distinctions between friends you could confide in and those they could not; some of your friends were trustworthy and others were simply not close enough for you to share information with:

Well, it depends on which one [friend]. Like some of them, some of them also have grandparents with Alzheimer's so they like know and then some of them like aren't really close with their families so they think its sweet and they hug her [grandma] back and all that stuff and then some of them are just like what are you doing. You know?

I didn't invite as many people over. I only invited close friends that already knew who she was. You know, just a new friend of mine walking in and seeing someone who doesn't really now what they are doing, it's kind of embarrassing for me.

Altered Leisure Activity

Many of you described limitations in activities with your friends and family members:

We wouldn't want to leave her alone. Sometimes when my parents couldn't get me to a friends house, and their friends parents couldn't pick me up, so I couldn't go to the movies or anywhere with them.

I feel like I can't do that as much. Cause, I don't know, she always gets mad about stuff. . . . If my dad's home, he can take care of my Grandma and then I can go out. . . . If my dad's away on a trip on business or something, then I have to stay home.

On Your Best Behavior

A few of you described the tendency of your family member to “behave” well when your friends or other guests were in your home:

When we had company, he was very nice. He seemed like when there was someone at the house, everything went back to normal. Like something clicked and everything went back to normal. That was weird for a little while. Until I figured out like seeing people that he knows he's seen like a while back, like it takes him back and it clicks and things go good, something like that.

Usually when people come over she doesn't really leave her room. She just like stays in there. So she doesn't really leave. You like have to force her to come out of her room a lot of the time cause she just wants to sit in there, and its hot in there, like during the summer my mom will be like no you have to come outside and sit around by the pool and get some sun and all that stuff.