# Stages of Resolution: Young Adult Children Coping with an Alzheimer's Disease Parent

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**ABSTRACT.** This study explores the experiences of 20 adolescent and young adult children between the ages of 16 and 34 who have a parent with Alzheimer's disease. Qualitative and quantitative analyses were conducted to compare participants' coping processes with their psychological status, knowledge of Alzheimer's disease, the functional level of the parent over time, and family dynamics. Grounded theory revealed 4 stages of sequential resolving that lead to the child's coming to terms with the parent's disease: (1) awareness, (2) explanation, (3) attribution, and (4) integration. Factors that were identified as important for healthy resolution included being able to fully integrate the patient and parent into one identity, having internal skills for managing adverse life events, and knowledge of the disease process. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: <getinfo@haworthpressinc.com> Website: <http://www.HaworthPress.com>* 

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## *INTRODUCTION*

Alzheimer's disease (AD) is a debilitating condition that has a profound impact, not only on the patient, but on the entire family. The responsibilities can be an emotional burden, affecting both the caregiver's psychological and physical well-being. Much of this has to do with the unique nature of AD. It is an insidious, degenerative, and progressive disease that leaves the physical aspects of the victim intact while robbing them of intellectual capacities.

The focus of research and intervention with Alzheimer's disease families has been almost exclusively with the primary caregiver. Extensive research has been conducted on the stress experienced by these caregivers, who are usually spouses or middle aged children. Zarit (1980) has defined the term "caregiver burden," an inclusive construct referring to the multiple physical and emotional stressors experienced by the primary care provider. Burden has been further factored into "objective" and "subjective" burden (Montgomery, Gonyea, & Hooyman, 1985): objective burden includes the financial strain of care provision and the physical labor involved, while subjective burden includes the caregivers' feelings of isolation, anger, guilt, depression, and loss.

Research has emerged indicating that the disease has a significant effect upon the structure of the family system. One study has shown that Alzheimer's disease impacts the family as a whole and how they perceive living with AD (Garwick, Detzner, & Boss, 1994). Such perceptions have revealed the stress on family members regarding the ambiguity and difficult nature of coping with someone who has the disease. Recent research on how a family comes to terms with Alzheimer's disease has outlined different stages of identification and coping. Differences in how each family member defines and makes meaning of AD has consequences for the family as a unit (Perry & Olshansky, 1996). Globerman (1995) reveals how childhood reputations follow siblings into adulthood, where their adult roles in the family are entrenched because of family history. Those children who were excused from family responsibilities in childhood appeared to be unencumbered as adult caregivers; their suffering over a family member with AD revealed itself as a sense of loss of self. Involved chil-

dren, on the other hand, described their burden in terms of the overwhelming pulls and demands made on them from caregiving. Research has stressed (Zarit & Zarit, 1982) the need for interventions with the entire family system. These investigations point out that with the "death of the mind" of the AD patient, the entire family sustains an overwhelming loss.

A subset of the caregiver literature has focused on the middle-aged children of the elderly (Brody, 1981; Silverstone & Hyman, 1979). To date, however, the specific impact of having a parent with AD on adolescent and young adult children has undergone little investigation (Weiler & Buckwalter, 1988). Some anecdotal notes have appeared in articles dealing with caregiving and AD (Lezak, 1978; Teusink & Mahler, 1984). Dwyer, Henretta, Coward, and Barton (1992) describe changes and fluctuations in the caregiving responsibilities of adult children over time. Yet few, if any, formal research studies are available on the coping strategies of young adults who have a parent with Alzheimer's disease. These individuals, while not usually primary care providers, have sustained the functional loss of a parent and may have been forced to assume unexpected caretaking responsibilities. This loss, in combination with recent research findings indicating the strong possibility of a genetic component to AD (Hardy, 1995; Reiman et al., 1996), makes the young adult children of patients vulnerable to genetic stressors. These include concerns over one day having the disease themselves and the implications of this on future plans such as marriage and children.

The closest parallel in the literature to the situation faced by the children of an AD parent addresses the concerns of offspring of persons with Huntington's disease (HD) (Dewhurst, Oliver, & McKnight, 1970; Folstein, Franz, Jensen, Chase, & Folstein, 1983; Hans & Koeppen, 1980). Research has consistently shown that HD children are at risk for psychiatric disturbances. For the adolescent, the lack of a role model may impair normal psychosexual development. Emotional independence may be more difficult to obtain, economic freedom may be restricted, and concerns about marriage may be confounded by a child's fear of developing the disease. For the young adult, the tasks involving separation from the family of origin may be made more difficult by the continuing demands on the family system for support.

Even though there has been little research covering the psychological impact of having a parent with AD on adolescents and young

adults, the population of AD patients with younger families continues to grow as early diagnosis and changing social patterns (i.e., second families) become more common. While AD is more prevalent at age 80 (1 in 5) than at age 65 (1 in 20), diagnosis as young as age 45 does occur (Terry & Katzman, 1983). As a result, increasing numbers of adolescents and young adults will become aware that one of their parents has AD. Issues such as anxiety, anger, stress, depression, and the need for altered coping strategies have been alluded to in the AD primary caregiver literature (Zarit, 1980). Even though adolescents and young adults are not usually primary caregivers, we hypothesize that these individuals are significantly affected by their parents' illness.

The purpose of the present study is to explore and describe the experiences of 20 adolescent and young adult children between the ages of 16 and 34 who have a parent with Alzheimer's disease. Qualitative and quantitative comparisons are made between the coping process of the children and factors such as psychological status, functional level of the patient over time, and family dynamics.

## *METHODS*

### *Subjects*

The participants in this study were 20 male and female (14 female, 6 male) volunteers between the ages of 16 and 34 (mean = 28) who have a parent with a diagnosis of Alzheimer's disease. They were recruited from families participating in the Alzheimer's research program in the GPRU (Gero-Psychiatric Rehabilitation Unit) at the VA Palo Alto Health Care System, local ADRDA (Alzheimer's Disease and Related Disorders Association) support groups, and other community resources. Those who volunteered were screened for participation by a semi-structured interview designed to explain what was involved in the study. Persons with a major mental disorder or illness were ruled out due to concerns that the interview process might exacerbate existing mental problems. Participants in this study were not the primary caregivers of the parent with Alzheimer's disease.

### *Procedure*

Participants completed a series of questionnaires assessing current psychological status, knowledge of AD, and learned resourcefulness.

A semi-structured interview was administered to explore subjects' personal experiences with the impairment of their parent-including family dynamics, marriage, social and developmental issues, future plans, and personal reactions to the disease. Comparison of these various measures served to help us understand the relationship between participants' psychological status, coping responses, and personal experiences of having a parent with AD.

### *Measures*

The affected parent's degree of impairment was rated by a clinical nurse specialist experienced in geriatrics and psychiatric/mental health nursing by means of the Reisberg Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982). Current psychological status of the subjects was assessed using the Symptom Checklist 90 (Derogatis, Rickels, & Rock, 1976). This 90 item self-report inventory is rated by the respondent on a five-point scale (0-4), ranging from "not at all" to "extremely." Subjects are scored on 3 indicators of distress: the Global Severity Index (GSI), the Positive Symptom Distress Index, and the Positive Symptom Total (PST). These indices each communicate in a single score slightly different aspects of an individual's emotional distress. The GSI is the best indicator of distress and combines information on numbers of symptoms and intensity of perceived distress. The PSDI corrects for number of symptoms and functions as a measure of response style. The PST is a count of the number of symptoms the patient reports as having experienced (Derogatis, et al., 1976). Subjects are also scored on nine dimensions of psychological symptomatology, including somatization, obsessive-compulsive and interpersonal sensitivity dimensions, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. The SCL-90 is a well-known and respected research instrument with good concurrent validity with other personality inventories, including the MMPI (Derogatis, 1977). It has advantages over the MMPI and other more elaborate measures due to its relative ease of administration, scoring, and interpretation.

Knowledge of Alzheimer's disease was assessed using the Knowledge Questionnaire, a 75-item true/false "quiz" on Alzheimer's disease, with statements like, "Alzheimer's disease is communicable or catching." Items assessed the respondents' knowledge of the etiology, diagnosis, symptoms, treatment, and prognosis of AD; a special sec-

tion assessed knowledge of legal and financial concerns. An early draft of the questionnaire was given to ten professionals in aging and to ten young adults in unrelated areas. Feedback was elicited on the questionnaires and incorporated into the present version. This revised version was piloted with ten additional young adults and ten gerontological health professionals. A moderately high level of internal consistency for the total scale was found (.85).

Learned resourcefulness was assessed using the Self-Control Schedule (Rosenbaum, 1980). This 36 item questionnaire measured participants' coping mechanisms by having them rate where they fit on a scale of − 3 to + 3 based on items such as, "Often by changing my way of thinking I am able to change my feelings about almost everything." Research findings have shown that the SCS is a reliable measure (Richards, 1985; Rosenbaum, 1980; Zauszniewski, 1995). Subjects scoring high on the SCS in comparison to low scorers were found to have an internal locus of control and to hold fewer "irrational" beliefs. In addition, these subjects were better able to control and tolerate noxious stimuli.

The primary source of data for this study was the semi-structured interview, in which clinical nurse specialists with extensive training and experience in geriatrics and psychiatric/mental health nursing elicited from each participant personal responses to the impairment of a parent. Topics included dating, marriage, family planning, orientation toward the future, social and developmental issues, heredity of AD, and coping interventions.

### *Analysis of Interview Data*

Each interview was analyzed utilizing the grounded theory method of qualitative analysis. It is not a substitute for quantitative analysis, yet it does offer a supplementary means of exploring data that is not easily quantified (i.e., interviews, written documents, and observations). This research format is particularly aimed at developing new concepts grounded within the data (Chenitz & Swanson, 1986). Wilson (1985) lists four steps the analyst is to use in the development of a grounded theory: (1) code the data by conceptualizing the underlying patterns and categories, (2) write analytic memos that reflect ideas about how the data, codes, categories, and relationships may possibly be connected to each other, (3) discover themes that emerge as a result

of coding and memoing, and (4) sort the memos and produce an outline that integrates all of the major ideas into a coherent scheme.

The present study used this grounded method by audiotaping and professionally transcribing the interviews verbatim for analysis. The transcripts were then reviewed for themes and patterns by systematically labeling, separating, and organizing the meaning in the text. Such coding ranged from simple categorical observations to more complex emerging themes. All interviews were independently reviewed by a clinical nurse researcher specializing in qualitative analysis in order to assess reliability. Emerging ideas were then tracked through analysis of future interviews. This process ultimately resulted in the development of a theory to describe the coping processes of adolescent and young adult children having a parent with AD.

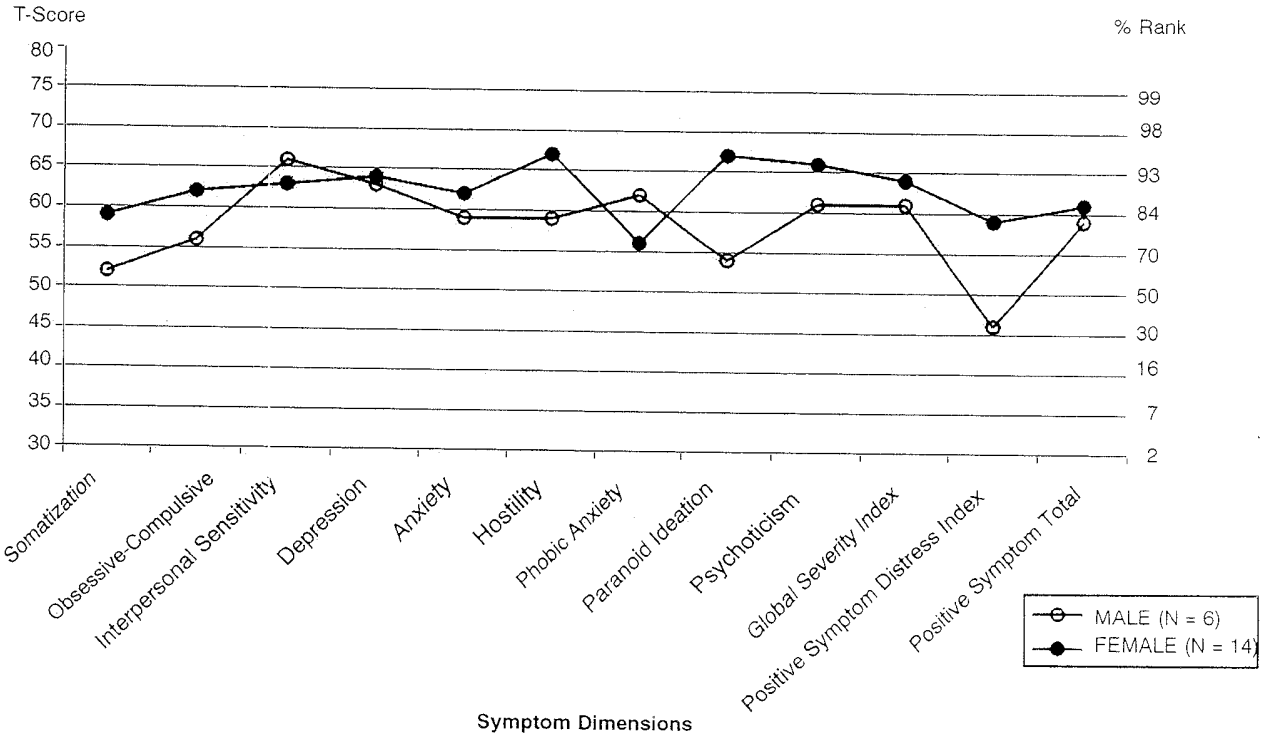
## *RESULTS*

### *Characteristics of Participants*

Fifty percent of the participants were married or in a significant long term relationship, 10% were still living at home, and 55% had children of their own. Eighteen subjects were Caucasian and 2 were Asian American. The average level of education was completion of partial college (45%). All reported their health status as good or excellent. Over half (55%) of the respondents reported experiencing physical discomfort such as headaches or neck pain. Ratings of the parents with AD on the Reisberg Global Deterioration Scale ranged from mild to moderately severe–over half (11 parents) with moderately severe deterioration.

T-scores were determined for each SCL 90 sub-scale by comparing them with normal male and female non-patient norms (Derogatis, 1977). All sub-scales corresponded to a T-score between 46 and 67, indicating that participants' stress levels were variable, but generally normal (see Figure 1). Even though there were only 6 male to 14 female participants, Derogatis (1977) has emphasized following gender appropriate norms due to the relationship between sex and self-reported levels of psychopathology. Scores were highest on interpersonal sensitivity, depression, anxiety, and hostility. Although the paranoid ideation and psychoticism sub-scales were above 93% for the female

FIGURE 1. SCL-90 Mean Symptom Profile of 20 Adolescents and Young Adults with an Alzheimer's Disease Parent



participants, it should be noted that two participants in particular raised the average by scoring very high on these items.

The average score of correct answers on the Knowledge Questionnaire was 72%. The greatest knowledge the participants had pertained to the genetic factors (89% correct) and general aspects of the disease (84% correct). The area of most difficulty was knowledge of treatment (59% correct). The remaining scores of correct answers were: general causes = 66%; diagnosis = 68%; legal issues = 61%; progression of disease = 75%. Participants' scores on the Self-Control Schedule ranged from −23 to 68, with a median score of 15 and standard deviation of 25. Rosenbaum's (1980) normative data from a sample of 111 American students in their early twenties revealed means of 25.9 and 27.5 for male and females respectively. No significant correlations were found between scores on the Knowledge Questionnaire, SCS, and GSI subscale of the SCL-90.

### *Qualitative Analysis*

The emerging themes from the qualitative analysis were categorized into 4 stages of experience for a young adult with a parent with Alzheimer's disease, a process that has been termed *sequential resolving* (see Table 1). Although the stages of this process may parallel the changes in the parent, the child may become stuck anywhere along the process. How the child deals with the parent's AD and his/her own

TABLE 1. Sequential Resolving

| | |
|---|---|
| 1. Awareness Stage: | "Is something wrong?" |
| a. Dismissal Phase: | "This isn't serious, is it?" |
| b. Realization Phase: | "Yes, something is significantly wrong." |
| 2. Explanation Stage: | "I need to find out what is wrong." |
| a. Decoding Phase: | "It's real, but what is it?" |
| b. Interpreting Phase: | "So it's AD. What does it mean for my parent and me?" |
| 3. Attribution Stage: | "Who is this person?" |
| a. Redefinition Phase: | "My parent is now a patient." |
| b. Selection Phase: | "Which conceptualization works best for me?" |
| 4. Integration Stage: | "My parent and the patient are the same person." |

reactions to it evolves continuously. The different stages–awareness, explanation, attribution, and integration, each address central ways the child comes to terms with the parent's Alzheimer's disease. While we have at present identified four stages, there may be even more, since in this sample all the parents were still living at home. Ultimately, the child needs to find a balance between resolving ongoing issues with the parent through the disease process while maintaining integrity of his or her own life.

The first stage develops at a time when the child is beginning to perceive basic functional and psychological changes in the parent. These symptoms, like the disease itself, are insidious: they appear inconsistently, are not global in nature, and are therefore easy to dismiss or attribute to another cause such as stress or fatigue. But as the disease progresses, the symptoms become more visible, forcing an emerging awareness of "something seriously being wrong." The symptoms of AD are no longer dismissible and must be dealt with. They can no longer be ignored or rationalized. Other family members, including the patient, the spouse, and other siblings, may be at the same stage or different stages in their awareness and understanding of the emerging symptoms. Family members may work together to either bring each other's awareness of symptoms up to date or to conceal the symptoms. For example, a sibling who spent part of every day with the AD father enhanced her brother's awareness by reporting the father's activities of daily living abilities to her brother: "You know, Tom, today Dad couldn't tie his necktie." An unaffected parent/spouse may hinder a child's growing awareness of symptoms by covering them up, quietly taking over tasks such as paying bills, and not informing the children.

Conditions that influence the awareness phase are the child's living situation, his/her knowledge of AD, the degree of exposure to the changes in the parent, and the nature and rapidity of those changes. Awareness generally comes earlier to children in closer geographic proximity because of much greater exposure to the symptoms and their consequences. The initial reaction may be to deny, ignore, rationalize, or excuse the changes in the parent's behavior. They may become cautious, wary, and watchful, while also dismissing behaviors they believe fit into a non-malignant category. For example, one child attributed his father's changing behaviors to his drinking habits and the possibility that he was having an affair.

Either a bulk of indismissible data or a precipitating factor causing marked confusion and disorientation (such as a fall or moving to a new environment) will move the child into the stage of realization. This phase is influenced by whether or not a child has prior knowledge of AD. At this point the child begins observing and making comparisons with the parent's previously normal behavior and relating the parent's symptoms to known information about AD. It is in this phase that the child becomes fully aware of the changes in the parent. The children may begin to confer with others for validation of their observations and concerns. They may gather and test observations. While there needs to be an acknowledgement that something is significantly wrong, they may still attribute the behaviors to non-malignant causes.

It is at the explanation stage that the child will either become actively involved or else distance him/herself from the parent and the disease. If the child chooses the former, the next step becomes establishing a definitive diagnosis and a physical explanation or meaning to the parent's behaviors. The child may take various initiatives including obtaining medical diagnostic work and assistance, sharing their observations and findings with the well parent, and involving other siblings or family members. If the diagnosis of AD is not accepted by the child, he or she may seek a second opinion and cling to a competing diagnosis–i.e., stress or depression. In extreme cases, the children become "lay experts" in AD. This may occur because of an intellectual defense against the loss, but more often it is a result of their attempts at accepting the illness and preparing for the future. It is at this stage that the participants may begin to take on more responsibilities and report being heavily burdened in their struggle to come to terms with AD. As one child expressed: "It made my mom expect more out of me. I guess it made me grow up faster."

Once the diagnosis has been accepted, the child recognizes that the "core" of the parent that was is slipping away. He may begin interpreting what the disease means for him and his parent. This is a time when grieving over the loss of the parent begins to take place. One coping mechanism to handle this is to look for signs that the "parent" is still there. A child may do this by clinging to indications that the parent still recognizes her. She may also realize that while the AD parent can no longer verbally communicate, there is still an emotional means of relating, e.g., "even though he may not know who I am or

cannot communicate that to me, I can still talk to him and know he understands."

The third phase of sequential resolving is the attribution stage. This term was chosen to describe the child's need to create a new identity for the parent. An important part of coming to terms with this is accepting the meaning of AD and who this person has become as a result. One of the most difficult tasks facing the adolescent or young adult child of an AD patient is learning to constantly redefine the parent. Gradually, the parent's behaviors become less and less representative of who the child once knew and more symptomatic of the disease itself. There are several conceptualizations the child may form, such as: "this patient is not my parent," "my parent is dead," or "this is still my parent that I care for and value." Resolution of the attribution stage is critical for healthy adjustment. Without resolution, the child may get stuck in this phase and not be able to cope with the stress and loss of a parent with AD. This requires grasping the progression of the disease and understanding that it can only be adapted to and accepted. Some children may even find a substitute parent, a person that they can go to once they feel that they have lost their mother or father to Alzheimer's disease. Children of AD must simultaneously redefine the parent as an AD patient, mourn the loss of the person that was, and adjust to the changes in the family system caused by the replacement of the parent with a patient.

A critical challenge at this stage is learning how to provide support for the well parent without a loss of attention to the child's own life and family. Often while redefining the parent, the child may put his or her feelings for the parent on a shelf, and deal only with the required tasks, i.e., "this is a patient whom I will care for but have no emotional attachment." Successful resolution involves recognizing the parent's status as a patient, allowing the space to grieve, and supporting the parent while also carrying on with his or her own life.

The fourth stage is when the child is able to fully integrate the patient and the parent into one identity, retaining both the experiences and memories of the parent that was and the present experiences of the parent with AD. In the prior stages, the child has struggled with coming to terms with past knowledge and experience and the current changes. At this point, resolution takes place through the understanding that the parent and the disease are part of the same person. This stage was not yet reached by the subjects in this study. We hypothesize

that successful resolution occurs later in the process, either by the time the parent has either reached a severe stage of deterioration or has died.

## *DISCUSSION*

An important factor in fully coming to terms with a parent who has AD is knowledge of the nature of the disease–its course, symptoms, and what treatment or care is available to the patient and the family. It is during the explanation stage of sequential resolving that they gain this understanding. The participants in this study had already passed through this stage, which would explain their solid Knowledge Questionnaire scores pertaining to the general aspects of the disease. However, scores were low on items pertaining to the efficacy of various treatments on Alzheimer's disease. Targeting education efforts in this area may provide children with a sense of control in managing the disease, while also encouraging a realistic awareness of the terminal nature of AD.

There was a wide variability in the Self-Control Schedule (SCS) scores. This is consistent with Rosenbaum's (1980) preliminary findings, which reflects the existence of large individual differences in self-control behaviors. The median score of participants in this study was 15, indicating that our participants had a repertoire of skills for managing adverse life events, but were within normal range. Studies have demonstrated that persons scoring high on the SCS have better coping skills when faced with negative life events and hence would experience fewer psychological symptoms and complaints (Fingerman, Gallagher-Thompson, Lovett, & Rose, 1996; Lewinsohn & Alexander, 1990). Intrieri (1994) has suggested that self-control skills may explain why some spouses adapt better than others to their role as caregiver for a cognitively impaired husband or wife. In the case of children or young adults with an AD parent, internal self-control skills might result in a smoother, healthier progression through the stages of coming to terms with the loss of their parent.

Results from the SCL-90 further suggest that participants were experiencing symptoms of depression, poor self-esteem, anxiety, and hostility. This is consistent with other literature that has identified anger, depression, and grief as emotions experienced by those caring for a loved one with Alzheimer's disease (Ponder & Pomeroy, 1996;

Rabins, Mace, & Lucas, 1982; Schulz, Visintainer, & Williamson, 1990). However, what is unique to a younger population with an AD parent is the presence of an out of sequence life event. While all children are eventually faced with the death of their parents, this particular group must confront losing a parent at an earlier stage in life. Furthermore, this loss is not sudden, but is experienced gradually as the parent progresses through the disease process. Acceptance and resolution may be difficult due to a belief that the loss of a parent is "not supposed to happen now." Nevertheless, the child may find him or herself assuming unanticipated responsibilities and roles within the family. For example, one participant felt he had lost his carefree years; another felt that as the eldest, she had the responsibility of taking on a leadership role in the family. These changes may come at a time when the child is seeking individuation and separation, resulting in a conflict between his or her needs and the needs of the family.

In order to address the unique concerns and experiences of a younger population of children with an Alzheimer's disease parent, we developed a year-long support group, throughout which the children's struggles with coming to terms with their parent's Alzheimer's disease were revealed. Literature has already suggested the positive effects of support groups for family members and caregivers of someone with Alzheimer's disease (Hinkle, 1991). The formation of a support group specifically for adolescent and young adult children would provide a useful means of addressing and encouraging healthy resolution.

In summary, results from the qualitative analysis revealed that children of AD parents who are able to process through the sequential stages and ultimately come to terms with their parents' Alzheimer's disease may reach a point of healthy resolution. Although we have identified four stages of sequential resolving, it is possible that each stage may not be passed through in order, and some stages may even be skipped. Adolescents or young adults who skip a stage may still come to terms with the loss of their parent if they have a firm foundation of knowledge of the disease and have the skills to manage adverse life events. This study suggests that future research and intervention specifically address the experiences and needs of a younger population.

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