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# Young Children in Early-Onset Alzheimer's Disease Families: Research Gaps and Emerging Service Needs

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## Abstract

Early-onset Alzheimer's disease (EOAD), defined as affecting those under age 65, afflicts between 200,000 and 500,000 people in the US. EOAD tends to be a fast-progressing and aggressive form of AD. There is a beginning body of research exploring EOAD patients' experience and needs, as well as that of their primary family caregivers, often spouses. However, there has been very little written about the experience and needs of EOAD patients' children, who because of the early onset, and increasing postponement of childbearing, may be latency-aged or in their early teens. This paper reviews existing and related literature in this area, and illustrates the psychosocial impact on children using the case of a 50 year-old father diagnosed with AD and his 16 year-old daughter and 11 year-old son. The need for increased research and program development to address these children's needs is discussed.

## Keywords

caregiving, children, early-onset AD, psychosocial impact

## Introduction

Early-onset Alzheimer's disease (EOAD), defined as affecting those younger than 65 years, afflicts between 200 000 and 500 000 people in the United States.<sup>1</sup> Early-onset Alzheimer's disease tends to be a fast-progressing and aggressive form of Alzheimer's disease (AD), affecting people likely still actively engaged in the labor force and in raising children. With the Alzheimer Association's recent statement that AD is the seventh leading cause of death for people of age 65 and older in the United States, increasing attention has been paid to research in this area, but relatively little is still known about the needs of patients with EOAD and especially of their young children.<sup>2,3</sup> This is surprising and worrisome because it is estimated that 250 000 American children of age 8 to 18 are family caregivers for a person with AD.<sup>2</sup> Furthermore, the number of child caregivers is expected to rise because of improvements in medical technology, the increase in single-parent households, and the postponement of childbearing.

There is a beginning body of research exploring EOAD patients' unique experience and needs, as well as that of their primary family caregivers, who are mainly spouses. Spouse caregivers of patients with EOAD have greater perceived difficulties with coping, less social support, and a longer duration of caregiving than caregivers of patients with late-onset AD (LOAD).<sup>4-6</sup> Caring for someone with EOAD may be more stressful because of additional responsibilities that caregivers have, such as maintaining the marriage, raising children, and developing their careers.<sup>7</sup> Many spouse caregivers of patients

with EOAD are baby boomers in the sandwich generation, who are caring for young children as well as aging parents.<sup>8</sup> Thus, caring for a spouse with EOAD is just one of their many caregiving roles, further increasing burden.

As a result of this additional burden on primary caregivers of patients with EOAD, young children in these families often assist with caregiving tasks.<sup>9</sup> Because in the case of EOAD the family is usually at a younger developmental stage, children of parents with EOAD may be latency aged or in their teens. This means that children are experiencing their parent's progressive loss of cognitive function and self-care abilities characteristic of AD throughout crucial developmental years. Young children of parents with EOAD may feel some of the following: shame about their EOAD parent's odd behavior, anxiety about stress in the parents' relationship, fear and grief with regard to the losses that the parent experiences, loneliness because the healthy parent has to focus more attention on the EOAD parent, frustration and confusion about role reversal, and worry about the chances of getting AD in the future.<sup>2</sup> However, there is very little

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specific and systematic research on the impact of this particular and unprecedented stressor on children.

In this article, we review the existing literature regarding the psychosocial impact on children who serve as family caregivers for parents with EOAD and, because of its extremely limited nature, also briefly describe a broader literature on children as caregivers. We then illustrate the psychosocial impact of EOAD on children by presenting an intervention we undertook with a family consisting of a 50-year-old man diagnosed with EOAD, his 40-year-old wife, 16-year-old daughter, and 12-year-old son. Finally, given the gaps in current research, we discuss the enormous challenges and opportunities for researchers and practitioners in researching, planning, implementing, and evaluating appropriate educational, supportive, and therapeutic services for families and children impacted by EOAD.

## Literature Review

This section first reviews existing literature on children as caregivers in general and then on children of parents with EOAD. Because very little research exists specifically on this latter topic, this review also briefly summarizes from other relevant bodies of literature such as family caregiving and LOAD, and children of parents with chronic illnesses other than AD, in order to contextualize these children's experience and needs and to identify potential areas for future research.

### Children as Caregivers

Relatively little has been written about young caregivers, generally defined as children and adolescents who are 18 years and younger.<sup>9-12</sup> The first and thus far only US count of young caregivers occurred in 2005. It found that at least 1.4 million children of age 8 to 18 were serving as family caregivers and over 50% of them were caring for a chronically ill parent or grandparent.<sup>13</sup>

There are several reasons that so little is known about child caregivers.<sup>14</sup> The hidden nature of child caregiving makes it difficult to determine its prevalence and incidence.<sup>15-18</sup> Because often children do not self-identify as caregivers, they are excluded from studies. Furthermore, many children do not disclose this information out of shame or out of fear of being removed from their families.<sup>19</sup>

Additionally, child caregiving is not well defined in the research. There is inconsistency regarding definitions of primary versus secondary caregiving and who is considered a child caregiver. Many studies look only at children 18 years and younger, but some have extended the age range to 21 and even to 25 because of recent trends of children living at home longer.<sup>9</sup> Child caregiving is not considered child labor by the International Labor Organization (ILO), and so it is rarely identified by United Nations Children's Emergency Fund (UNICEF) and other international organizations as a social problem that needs to be addressed.<sup>20</sup>

The most extensive research on child caregivers has been done in the United Kingdom by Becker and colleagues.<sup>21-23</sup> Their findings indicate that young caregivers can be negatively affected by caring in complex ways. Caring for a parent is often a physical challenge. Caregiving also restricts contact with peers and others, impairing young carers' social development. In addition, many of these children, because of the extent of their responsibilities, miss significant amounts of school, restricting their educational opportunities. Finally, there are emotional and psychological ramifications from the role reversal of caring for a parent and witnessing parents in an impaired condition. However, children can also derive a sense of well-being and self-worth from caring for their parent, but much depends on the support and reaction they have from others, including professionals.<sup>24,25</sup> Thus, a growing body of research in this area is increasingly focused on the development of supportive interventions for these young caregivers.<sup>17</sup>

### Young Children Caring for Parents With EOAD

One would expect the experience of children with a parent with EOAD to be unique and particularly challenging because of the chronic deterioration of the parent's key faculties involved in maintenance of the parental role, the resulting progressive loss of connection and relationship between the child and EOAD parent, and natural fears that the child would himself or herself eventually develop the condition. To our knowledge, there are no published studies specifically exploring the experience of children of parents with EOAD. However, we found 3 articles less directly addressing the issue. The first is a case study of a 43-year-old widowed mother diagnosed with early-onset dementia whose teenage son experienced her deteriorating parental capacity for 2 years before moving in with friends. While the case study does not elaborate on his experience, a consultant thoughtfully discusses the impact of having an ill or cognitively impaired parent on a child or adolescent, and the importance of having service providers encourage families to attend to their needs.<sup>25</sup> The second study which explored the effects of caring for a demented relative at home on the parent-adolescent relationship and family dynamics in general included 2 families with adolescent children of a parent with EOAD.<sup>26</sup> One adolescent was a 15-year-old girl living with her parents whose father had been diagnosed with AD 8 years earlier. Mother was highly stressed. The daughter had few caregiving chores, missed the close relationship she shared previously with her father, and felt some tension toward her mother, feeling that the latter was taking her stress out on her. The second adolescent, a 13-year-old boy, lived with his adoptive parents. His mother was in the early stages of AD. Father did not experience caregiving as stressful, but felt that it was negatively affecting his son, who was bothered by his mother's erratic behavior. The son and father now enjoyed a closer relationship. The study did not distinguish between the children whose parents rather than grandparents had AD. Overall findings were that the adolescents showed empathy and respect for the caregiver parent and felt an enhanced

connection to them. They also noted restrictions on their own and the family's activity as a result of the caregiving situation, which at times caused stress. Caregivers assessed less of an impact of the caregiving situation on their children than the children themselves did.

The third relevant study assessed the long-term impact on adults of having cared for a parent or other adult relative as children. In all, 24 persons were interviewed about their experiences and asked to complete questionnaires on their mental health and parent-child relations. Only 1 of these participants had cared for a parent with AD. While most participants did not exhibit poor mental health, about 42% had high depressive scores, indicating that some child caregivers might be at risk of depression in adulthood.<sup>9</sup>

### *Family Caregiving and LOAD*

There is a vast body of literature on family caregiving in LOAD. Caring for a family member with AD can be extremely stressful, not only for the primary caregiver but also for the entire family system.<sup>27-31</sup>

Research on the impact on children living with an extended family member with AD indicates increased empathy for the elderly, greater maturity, and greater assertiveness and selectivity with peers compared to that of noncaregiving peers.<sup>10,32-34</sup> In addition, caregiving tends to enhance family cohesion. Along with these benefits, however, there may be disadvantages, such as potential interference with the teen's ability to explore his own separate sense of identity and to successfully detach from his parents.<sup>10</sup>

### *Children of Parents With Chronic Illnesses Other Than AD*

Another body of research has looked at the experiences of children who live with a parent with a chronic illness, such as cancer, HIV/AIDS, depression, or drug addiction.<sup>14,15,35,36</sup> One study reported decreased academic performance, poorer concentration in school, increased school absences, and increased tardiness.<sup>12</sup> Caregiving children are less likely to participate in mainstream hobbies, sports, and social activities compared to young noncaregivers because they are needed at home to help.<sup>18</sup> Child caregivers also report social isolation because they fear being rejected or stigmatized by their peers.<sup>20,37</sup>

Children's relationships with their ill and healthy parents were found to be related to their mental health in adulthood.<sup>11</sup> Adults who had been child caregivers reported that they received less emotional warmth, less empathy, and less caring from their parents in childhood than those who were noncaregivers as children. They also reported more overprotectiveness from their parents than adults who were noncaregiving children.

Children's ability to cope with a parent's chronic illness increases with age.<sup>38</sup> A child's ability to cope with parental illness is correlated with the coping ability of both parents, the severity of the illness, and the degree of depression in the ill parent.<sup>38-40</sup> Caregiving stress can be mitigated by the child's relationship with

his or her parents,<sup>41</sup> degree of satisfaction with his or /her social support,<sup>24</sup> and sense of choice about caregiving.<sup>17</sup>

Much of the research on child caregiving has focused on the negative impact it can have on a child, but positive aspects of early caregiving have also been identified.<sup>42,43</sup> Children as young as 10 years old caring for parents with illnesses such as cancer, multiple sclerosis (MS), and arthritis, have reported that caregiving strengthened their relationships, increased their insights into the illness, improved their spiritual growth, increased their coping skills, and gave them a sense of pride and identity.<sup>17,37,43</sup>

Even though there is very little specific information on children of parents with EOAD, studies of children with a grandparent with AD or parents with other types of chronic illnesses alert us that while there can be some positive aspects to caregiving, caring for a chronically ill parent can have a significant impact on a child's physical, social, academic, and emotional life. The particular stressors of EOAD make this even more likely, as we illustrate with a clinical case example.

### **The Case of 2 Child Caregivers of a Parent With EOAD**

A young family dealing with EOAD enrolled in a study evaluating a counseling and support intervention for Latino family caregivers of persons with AD. A bilingual social work PhD student administered the intervention, known as the New York University Caregiver Intervention (NYUCI), which involves 3 components.<sup>31,44</sup> The first component is 6 individual or family counseling sessions, depending on caregiver's needs and preference, undertaken in the space of 4 months. The second component is participation in an ongoing support group such as those hosted by the Alzheimer's Association. The third component entails ad hoc counseling, consisting of ongoing consultation, case management, and referrals at the behest of the caregiver or any participating family member. The major aims of the NYUCI are psychoeducation, enhancement of social support for the primary caregiver, promotion of communication and problem solving within the family, and concrete planning around patient care.

Juan López was diagnosed with EOAD at the age of 46 and is now 50 years old. María López, his wife and primary caregiver, is 40 years old and works full time as a manager in a doctor's office. They have 2 children: Emilia, 16, and Carlos, 12.

María enrolled in the study as her husband's primary caregiver, and she participated in the 3 intervention components. This case review synthesizes clinical information from 2 individual sessions, 4 family sessions that included her and the 2 children, and ongoing ad hoc counseling by phone and in person over the course of 18 months.

María is a loving, intelligent, resourceful mother and wife. Emilia and Carlos are extremely articulate, expressive, and responsible children, consistently demonstrating wisdom beyond their years. They reported that Juan had always been a caring father and husband who took his family to church weekly, played drums in the church band, and worked full time

as an emergency medical technician (EMT) and cardiopulmonary resuscitation (CPR) instructor. Once he developed EOAD, however, his personality and behavior changed. He became forgetful, confused, irritable, impatient, and paranoid.

Eventually Juan had to stop working and was no longer able to manage the family's bills and finances. María became the family's primary breadwinner. Because of Juan's young age, he was not yet eligible for his pension without penalty. While he received some payment for disability, he lost 70% of his income. Initially he was denied social security because of his young age, but eventually sought legal assistance to appeal the denial. As a result, the family's finances decreased drastically. María accepted additional responsibilities at work in order to increase her salary, which made her work life more stressful. She was unable to pay for the vacations, toys, and clothes the family had once enjoyed. In fact, she had to visit a food pantry at one point and was unable to go to other pantries because of her work schedule.

The family reluctantly adapted to Juan's decreasing ability to participate as an adult in the family. His increasing dependence was accompanied by an increase in the children's parentification as Emilia and Carlos took on more adult responsibilities and became secondary caregivers. For example, while María was at work or running errands, Emilia and Carlos supervised their father at home or at church. In addition to taking care of their father, both children were expected to take over a significant number of chores, such as cooking, cleaning, and laundry. The children noticed that their mother was often exhausted and irritable, and they tried to help her care for their father as much as possible. In addition, María was coping with her own health problems, hearing loss and chronic back pain, which contributed to her stress.

In the family sessions, which they eagerly attended, wanting an opportunity to talk about their experience, Emilia and Carlos reported being worried about their father's deterioration, their mother's increasing stress, and their own chances of developing EOAD, especially because both their father and their paternal grandmother had this diagnosis. Their grandmother had died 5 years earlier. Both children experienced sadness, confusion, loss, anger, resentment, depression, shame, and social isolation. They were hesitant to confide in their peers about their father's EOAD, because of fear of how they might react. Thus, they felt isolated in their struggle. They rarely invited friends to their house, in part because of shame about their father's strange behaviors and in part because it stressed their mother to have guests in the home. The emotional bond between Emilia and Carlos deepened as they increasingly relied on each other for emotional support.

While there were similarities between Emilia and Carlos, their responses to their father's EOAD also differed in some ways. Emilia felt frustrated and overwhelmed by the decrease in money and increase in chores. When her mother was at work she managed the household and cared for her father and brother. Emilia complained that this interfered with her social life, schoolwork, and after-school activities. She had fond memories of going on father-daughter outings when she was

younger, and then her father stopped planning them as his EOAD worsened. Emilia was grieving the loss of her previous relationship with her father. In addition, with Juan's increasing memory loss, María felt like her husband was slipping away from her. As a result, she depended on Emilia for companionship and conversation, placing further responsibilities on this teenage girl. In the family sessions, with the guidance of the social worker, Emilia was able to articulate her feelings, and María became aware of the stresses Emilia was under and of the imperative of enlisting more appropriate social supports for herself.

Carlos reported feeling sad and angry much of the time. He had difficulty understanding the AD-related problematic behavior that his father exhibited, such as hiding small electronics from Carlos, taking credit for chores Carlos completed, or placing half-eaten food in odd places like sock drawers and the bathroom. Carlos was able to keep his grades up, and he focused on his schoolwork as a way of coping. He struggled with weight gain because of the stress he felt. He explained that he felt sad because his father refused to hug and kiss him, and at times, he acted like he did not know Carlos. He remembered his father as fun and affectionate before the EOAD, and he was experiencing grief at the changes he witnessed in his father.

### *Intervention's Theoretical Framework*

Our understanding of Carlos' and Emilia's experience and our subsequent intervention are based on several theoretical frameworks: life-course perspective,<sup>45</sup> family systems theory,<sup>46</sup> and structural family therapy.<sup>47</sup>

The life-course perspective evaluates how the timing of events affects individuals and families. Events are considered to be off time when they happen too soon or too late to a family or individual, and they are on time when they occur at a developmentally appropriate time. In the case of EOAD, adolescent children often end up caring for their parent with Alzheimer's, which is a nonnormative event, or an off-time event in the life of a child.

The life-course perspective was used to normalize the responses that Emilia and Carlos had to the changes in their family's lifestyle that resulted from their father's EOAD. Emilia and Carlos struggled with adapting to their father's behavioral and cognitive problems, their mother's increased stress, the limitations on their activities, the decrease in financial resources, and the increase in family conflict. Because having a parent with Alzheimer's is a nonnormative event for young children, they are likely to have difficulty coping with EOAD. Integrating this perspective into the intervention reminded María and the children that supervising their father and managing the household was a developmentally nonnormative event and was therefore understandably stressful for them.

A family systems approach emphasizes the interdependence among family members and underscores that any change or stress in 1 member will have corresponding repercussions for all others. This perspective again helped to render the changes and stress that all members of the family were experiencing as



understandable and expectable, enabling the family to work through the frustration, guilt, and confusion they experienced.

During the family sessions, María, Emilia, and Carlos were encouraged to identify family and friends who could provide support for them. María identified 2 of her siblings and a counselor at church, Emilia identified her older female cousin, and Carlos identified his best friend from school. María was hesitant to ask for help from family and friends, so the social worker encouraged her to invite her relatives to attend 1 of the family sessions. An older niece did attend, and the social worker was able to model for María how she might ask for help. In the session, the niece offered to teach María how to drive, since Juan could no longer safely do so. María was subsequently able to reach out to several family members and enlist their help in specific tasks such as spending time with Juan, driving the children to activities, and assisting with shopping and cooking. María also called the mother of Carlos' best friend to inform her of Juan's diagnosis and the impact it was having on Carlos. This bolstered support for Carlos and helped reduce his isolation.

Structural family therapy was used to understand and explore the way the family had been reconfigured as a result of the EOAD. As Juan's illness progressed, he had moved out of the parent subsystem. María had responded by relying more and more on the children to fulfill parental functions of oversight and running of the household. Consequently, Emilia and Carlos had experienced role reversal with Juan, and both became parentified children. Intervention with this family focused on restructuring the family to de-parentify the children and to provide support to María in her role as wife and mother from more appropriate sources. María began to decrease her expectations of the children and to rely more on adult social supports such as her sister, her in-laws, and her church members. She was educated about the risks of leaving the children alone at home to supervise their father while she was at work. María was also encouraged to increase Juan's participation at his social day treatment program from 2 to 5 days a week. This ensured his safety and stimulation for large portions of the day, allowing her some respite and ability to focus on her job, and reducing pressure on the children to supervise him after school.

In order to help the children return to the child sub-system, the counselor encouraged them to join after-school activities. This increased their contact with peers, and because they were not at home as much to provide supervision for their father, reinforced for María the need to have Juan in the adult-day program. Carlos took up piano lessons, joined a weight-loss and sports program for children, and spent more time with his best friend. Emilia took dance classes, participated in cheer-leading, started dating, and enjoyed exploring the city with her friends. Both children began to enjoy their increasing age-appropriate freedom and independence. These activities helped to reduce their loneliness and isolation and provided respite for them from the stresses of caring for their father.

Additionally, with the support of the social worker, the children began to accept their father's transition out of the parent subsystem into a position of special status. He could no longer

function as a parent, but he was not a child either. They recognized that they could no longer depend on him as the adult who drove them to activities, cooked for them, disciplined them, and engaged in supportive conversations. Discussions in the family sessions focused on helping them to develop a new way of relating to him that would necessarily continue to evolve as the EOAD progressed.

For the second part of the intervention, María was referred to an existing support group affiliated with the center where Juan attended the day program and which was very close to her work. However, our search for supportive services for Carlos and Emilia underscored the dearth of services available to young children dealing with EOAD parents. In the New York City area, we could find no support groups. The only resources available were a chat room and bulletin board through a Web site specifically for teens set up by the Alzheimer's Foundation. We were able to locate a 1-week sleep-away summer camp in Oklahoma, created by a mother with EOAD for her young son to address this gap in services. We secured a grant for airfare and camp fees to send both Carlos and Emilia in the summer of 2008. They reported a positive experience primarily from being with other children who shared their experiences and from learning new strategies for living with a parent with EOAD. For example, they were taught easy recipes to prepare meals at home and specific techniques for interacting with a parent with AD.

The dearth of supportive services for young children of parents with EOAD we encountered is not surprising, given the dearth of basic research exploring these children's experience, but underscores the need for further work in this area.

In terms of the third part of the intervention, María made good use of the ad hoc counseling, contacting the social worker at critical points in the progression of Juan's illness for information and support. Interventions made maintained focus on supporting María in the parental position, de-parentifying Carlos and Emilia, facilitating the processing of their feelings around the changes their father and therefore the entire family continued to experience.

## Conclusion and Implications

There are as many as 500 000 people in the United States diagnosed with EOAD, and approximately 250 000 children caring for a loved one with AD. There is a growing body of research on the impact of EOAD on the patient and caregiver, who is usually the spouse. However, very little has been published about the children of a parent with EOAD. Given what is known about the effects of caregiving on children and the unique characteristics of EOAD, much research on the impact of EOAD on children, who are likely to be experiencing unique and unprecedented challenges, must be undertaken. The existing related literature on child caregiving suggests that while there can be some positive outcomes, caregiving for a parent can be a significant stressor, something this case example underscores. Basic areas to explore include the number of children affected, and the impact on their social, emotional,

physical, psychological, and academic development and later functioning from having a parent with EOAD. Furthermore, knowing that risk factors for increased caregiver burden and depression in adults include being female and economically disadvantaged,<sup>31,48,49</sup> the impact of gender, age, and socioeconomic status on these children's particular experience must also be explored.

There are limited resources and services currently available to support children with a parent with EOAD. Research is fundamental for fulfilling the urgent need of developing, implementing, evaluating, and replicating appropriate interventions and broader policies to meet the unique needs of these child caregivers.<sup>50,51</sup>

### Author's Note

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