

# Early Caregiving and Adult Depression: Good News for Young Caregivers

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**Purpose:** Limited information is available on the effects of caregiving experiences on the adult development of caregivers under 21 years old in the United States. The current study provided an examination of the effects of youthful caregiving on the mental health of these persons when adults. **Design and Methods:** Twelve individuals, 23 to 58 years old, were given brief phone interviews with semistructured questions, and then they completed questionnaires on their early caregiving experiences and current mental health. To be included, respondents must have provided primary caregiving assistance (i.e., bathing, dressing, feeding, etc.) for at least one parent when the caregiver was under 21 years old. **Results:** The findings showed that individuals were young caregivers for parents with a number of problems, ranging from dementia to drug abuse. Individuals reported more positive mental health than negative mental health, and only two individuals had scores indicative of clinical depressive symptoms. **Implications:** It appears that early caregiving experiences may not result in universally negative consequences in the adulthood of young caregivers.

**Key Words:** *Adulthood, CES-D, Well-being*

There is no doubt that the caregiving role can be stressful for individuals, and the stressors of caregiving are greatly enhanced when one is caregiving for a relative with a dementing illness (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998). However, what happens when the caregiving experience starts much earlier than adulthood? Despite the abundance of research on caregiving, little research exists on early

caregiving experiences and the long-term impact on the young caregivers' adult development and aging. The only research related to early caregiving that has received notice in the gerontology literature is that of extended family members' (i.e., adolescents) experiences of "informal caregiving" (Beach, 1997; Pruchno, Peters, & Burant, 1995).

Estimates range from 19,000 to 51,000 individuals under 18 years old are primary caregivers for parents and/or grandparents in the United Kingdom (Dearden & Becker, 1999). Large surveys conducted in the United Kingdom showed that the average age of an early caregiver was 12 years old (e.g., Dearden & Becker, 1998). There is no precise information on the prevalence of early caregiving in the United States, as no formal national study of this problem has been conducted. Gates and Lackey (1998) found that children as young as 10 years old were providing primary care to a parent in American samples. L. Bauman has found that 35 children from 8 to 12 years old provide bed care for their mothers with late stage AIDS (personal communication, September 11, 2000). In a new survey of family caregivers in New York City, researchers have found 28 individuals between ages 18 and 21 were young caregivers (A. Kuerbis, personal communication, September 11, 2000; United Hospital Fund, 2000).

The question of importance in this study is "What are the long-term effects of early caregiving on individuals' adult mental health?" One study suggests that up to 75% of young caregivers develop psychological problems as adults (Frank, Tatum, & Tucker, 1999), particularly if care recipients had mental illness issues or alcohol and/or drug-related problems. Additional information to answer the above question is limited. This study provides preliminary data in an ongoing investigation on this topic.

## Methods

### Participants

In order to qualify for the study, individuals must have provided primary caregiving assistance (i.e., bathing, dressing, feeding, etc.) for one or both of their parents when the caregiver was under 21 years old. Eighteen individuals responded to the advertise-

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ments. Fourteen individuals qualified to participate in this study, and all 14 completed the study. Only 12 individuals are included in the analyses, because at the time of the study two individuals were under age 21, the definition of adulthood in this study. The sample included 11 women and 1 man, and the sample was primarily Caucasian (93%). The average age of participants in this study was 39.3 ( $SD = 13.5$ ) years old, ranging from 23 to 58 years old. All individuals had completed high school, and about half the sample had attended college. Individuals had a socioeconomic status that reflects middle-class workers. Eight participants provided primary care for their mothers, 1 participant provided primary care for his or her father, 2 participants provided primary care for both of their parents, and 1 participant provided primary care for a grandparent.

### Materials

**Early Caregiving Experiences.**—I assessed the early caregiving experiences with semistructured questions, Likert responses, yes or no responses, and open-ended questions in two formats: phone interview and questionnaire. The caregiving experience phone interview and questionnaire are available upon request.

**Mental Health.**—I used the Center for Epidemiologic Studies–Depression scale (CES-D; Radloff, 1977) to assess both positive and negative mental health. I used the well-being subscale of the CES-D to measure positive mental health. Coefficient alpha was .69 for the CES-D well-being indicator (note that removal of item 4 does increase coefficient alpha to .82, but item 4 was included in the analyses to compare with prior research). I used the depression subscale of the CES-D (excluding item 14, which confounds with interpersonal relationships; Krause, Herzog, & Baker, 1992) to measure negative mental health. Coefficient alpha was .88 for negative mental health.

### Procedures

Individuals learned about this study from advertisements in local and national caregiving newsletters, such as the *Take Care* publication from the National Family Caregivers Association and the caregiving newsletter distributed by the Baltimore County Department of Aging, brochures at local physicians' offices and adult centers, or by word of mouth. I provided contact information on all advertisements. Once individuals contacted me about the study, I conducted a semistructured interview over the phone. All individuals who qualified on the basis of the phone interview agreed to participate and were sent a package of questionnaires with a self-addressed stamped envelope to return to me upon completion of the packet. The packet of questionnaires took no more than 30 min to complete and included a measure of early caregiving experience, a measure of mental health, and other measures that

are part of an ongoing study on this topic. There was no monetary compensation available for participants' time and efforts.

### Results

The average age for early caregiving occurred in early to midadolescence ( $M = 14.0$ ,  $SD = 4.4$  years old). However, the range of ages showed that the caregiving experience can begin in childhood (range = 7 to 20 years old). Second, the majority of caregivers were women (93%). Third, the duration of the caregiving experience was, on average, 4–5 years ( $M = 4.7$ ,  $SD = 4.4$  years), which would cover most of adolescent development. Most important, the majority of the sample provided complete assistance with basic activities of daily living including bathing, dressing, feeding, and helping their parents with going to the bathroom (including bed pans). This information is consistent with the studies from the United Kingdom (e.g., Dearden & Becker, 1998) and the American samples (e.g., Gates & Lackey, 1998).

The participants reported a wide range of reasons for their parents' needing primary caregiving assistance. Different types of cancer including breast cancer and ovarian cancer were the most frequent reason for early caregiving, followed by arthritis and mental health problems. The majority of the sample had parents with chronic conditions that lasted a long period of time, and caregiving ended when the parent died. A few participants reported that their parents' conditions were acute and that recovery had occurred.

An important question in this study was "What is the adult mental health of early caregivers?" The mean score for positive mental health was 5.8 ( $SD = 2.1$ ); this score reflects the halfway point for the range possible on this scale (0 to 12). The mean score for negative mental health was 1.2 ( $SD = 1.9$ ); this score is very low on a scale with a range of 0 to 18. Higher scores mean that more of the construct is present. Individuals were consistently more likely to report positive mental health during the past week than negative mental health,  $t(11) = 5.76$ ,  $p \leq .0001$ . When compared with prior studies that do not separate positive and negative mental health, the total CES-D score for this study had a mean value of 9.7 ( $SD = 6.2$ ). This is below the cut-off value of 16 that is considered the lower end of clinical depressive symptoms (Hooker et al., 1998). Although the sample is small, it appears that individuals with the highest depressive scores had parents with emotional and drug abuse problems, regardless of duration of caregiving or time since completion of caregiving (see Table 1).

### Discussion

Little attention has been paid to the caregiving experience of younger caregivers, those who provide primary care for one or both parents when under 21 years old. How does the early caregiving experience

Table 1. Participants' Early Caregiving Experience and Current Mental Health

Age Began Caregiving (years)	Parent's Problem	Duration of Caregiving (years)	Time Since Caregiving Ended (years)	Current Age (years)	Participant Current CES-D <sup>a</sup>
7	Arthritis and/or diabetes <sup>b</sup>	2	47	56	13
7	Alcohol, drugs, depression	15	2	24	20
9	Alcohol, drugs	5	11	25	22
13	Fractured vertebrae	4	29	46	8
14	Adrenoid glands removed	4	35	53	4
14	Depression, anxiety	1	32	47	5
15	Rheumatoid arthritis	12	7	34	5
16	Cancer	1	41	58	12
17	Cancer	2	30	49	4
17	Stroke	3	3	23	9
19	Parkinson's disease and/or COPD <sup>b</sup>	5	7	31	10
20	Alzheimer's disease	2	3	25	4

Notes: Higher scores mean that more of the construct is present. COPD = chronic obstructive pulmonary disease.

<sup>a</sup>Some prior research does not assess both positive and negative mental health with the CES-D. Therefore, the total score for all 20 items was calculated for comparison purposes.

<sup>b</sup>Two individuals took care of both parents, so this reflects two separate individual's illnesses.

effect adult development and aging? This study was a first attempt to address this question. Results should be viewed with caution as this is a preliminary investigation of ongoing research on this topic. First, results provide hope for individuals with early caregiving experiences. Overall, the sample reported more positive mental health than negative mental health, providing results similar to research on spouse caregiving (Shifren & Hooker, 1995) and adolescent informal caregiving of grandparents (Beach, 1997). The majority of the sample reported CES-D scores below the cut-off for clinical depressive symptoms. The only exception appeared to be early caregivers for parents with both emotional and drug abuse problems. These individuals indicated that they provided both primary physical assistance and extensive emotional support to their parents. Prior research indicates that adults with the most mental health problems tend to be from families with parents who had mental health problems including depression and drug abuse (Frank et al., 1999). Note that three individuals did report health problems including depression, Parkinson's disease, and chronic fatigue syndrome. Therefore, this small sample did not consist only of individuals in good health. The mental health scores show that the early caregiving experience may not affect mental health in adulthood in a universally negative and pervasive manner.

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