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## PURPOSE

The purpose of this exploratory analysis was to investigate the characteristics of family caregivers who self-identified as the person chosen by their family for the caregiving role – the “Chosen Child” caregiver. Examining the Chosen Child caregiver is important since he or she may be under a unique type of stress due to familism and/or lack of choice.

## KEY FINDINGS

Chosen Child caregivers perceived more frequent emotional distress and reported receiving less respite care support from family and friends than child caregivers who did not identify as Chosen Child.

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## The Chosen Child: Characteristics of Informal Caregivers Selected at an Early Age to Provide Care to Family Members



## BACKGROUND

Family caregivers assume a critical role in caring for older Americans living at home, and are a vital component of long-term care.<sup>1</sup> Informal caregivers help their care recipients with activities of daily living, health care activities, and complex medical/nursing tasks.<sup>2,3,4</sup> While caregiving can be a source of joy and fulfillment, for many family caregivers it is also associated with considerable burden, depression, and anxiety, which can compromise the caregiver’s mental health and physical health.<sup>5,6,7,8</sup>

### Familism, Coping, Choice, and the “Chosen Child” Caregiver

Familism is a multidimensional concept that involves a person’s beliefs; interests; and prerogatives embedded in family core values, such as strong family identification, attachment, mutual support, family obligation, and

familial interconnectedness.<sup>9</sup> Pearlin's caregiver stress and coping model considers people's beliefs to be an important influence on their mental health.<sup>10</sup> As a key factor in explaining family roles and obligations, familism can have both a positive and negative effect on caregivers' health and well-being.<sup>9</sup> For example, Cox and colleagues found that familism has a positive influence on caregiver well-being when the caregiver perceives that the family is a strong source of support.<sup>11</sup> However, other studies have found familism to be associated with higher levels of depression, more emotional distress, and poorer subjective physical health.<sup>12,13,14</sup>

When emotionally distressed or burdened by caregiving, caregivers can attempt to improve their quality of life through various coping strategies.<sup>15,16</sup> For example, an active coping strategy includes attempts to solve or modify problems through planning, acceptance, and help-seeking.<sup>17,18</sup> Receiving respite care, social support, and counseling are a few examples of the help that is available to improve coping and to reduce the negative effect of caregiving and/or familism on a caregiver's emotional and physical health.<sup>3,18,19,20</sup> The opposite of active coping is avoidance coping, in which a person attempts to avoid problems often coupled with a self-management approach and/or denial of problems.<sup>12,21</sup>

Familism has been found to be associated with avoidance coping, which several researchers believe is a key reason why familism results in poorer outcomes for mental and physical health among caregivers.<sup>22,23</sup>

Other risk factors for negative outcomes associated with familism are a sense of obligation and a lack of choice in taking on the caregiver role.<sup>24,25</sup> Sayegh and Knight (2010) found that a significant proportion of familism's unfavorable effect on caregiver outcomes was due to feelings of obligation.<sup>22</sup> Additionally, Schulz et al. (2012) found that lack of choice in becoming a caregiver was associated with higher levels of emotional stress and physical strain, after controlling for multiple confounders including level of care, care recipient (CR) primary health condition, and demographics.<sup>23</sup> While familism may act as a cultural endorsement of the caregiving role, individuals who self-identify as the person at an early age chosen by their family for the caregiving role ("Chosen Child") could be driven to accept the role out of a sense of family obligation or duty.<sup>20</sup> Therefore, because the "Chosen Child" knew of their caregiving obligation since childhood, he or she may perceive a lack of choice in having to provide care, thus exacerbating their own risk for negative outcomes.

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## METHODS

### Data Source

We used survey data collected from caregivers who are the CRs' children. Survey data were collected in December 2016 from a random sample of informal caregivers who were participants in the Administration for Community Living's outcome evaluation of the National Family Caregiver Support Program (NFCSP).<sup>26</sup> The NFCSP is a Federal program designed to support informal caregivers by providing two core services: 1) Caregiver education/training, individual counseling, and support groups to help caregivers better manage their responsibilities and cope with

the stress of caregiving, and 2) Respite care provided either at home or at adult day care facilities, so that caregivers can rest or attend to their own needs. The evaluation's study sample consisted of 1,568 caregivers. The caregivers' relationships to the CRs was 43% spouse (n=678), 42% child (n=652), 2% in-law child (n=37), and 13% other including grandchildren and friends (n=201). More information about the Outcome Evaluation of the NFCSP and the development of the sample of participant caregivers for the evaluation is available on the Administration for Community Living web site.<sup>24</sup>

## Determination of Chosen Child

The survey instrument for the NFCSP outcome evaluation included a question developed by Rozario and DeRienzi (2008) that operationalized caregivers' beliefs about their caregiving role. Each of the 652 child caregivers were asked to rate how well the following statement fit with their beliefs about their caregiving situation: "I was chosen by my family as a child to provide care for all my family members." The caregivers that responded "Definitely true" were categorized into the Chosen Child group.



## Characteristics Analyzed

The sample of caregivers for this exploratory analysis consisted of 646 child caregivers. While the evaluation had 652 child caregivers, six were excluded due to missing responses to the Chosen Child question. Among the 646 caregivers, we examined responses to the Chosen Child question by gender and race. We also examined the recent use of NFCSP caregiver educational services and NFCSP respite care by Chosen Child response among a subgroup of caregivers. More specifically, NFCSP service use could only be examined among 79% of the full sample of child caregivers due to the design of the Outcome Evaluation, which had a comparison group of caregivers that had never used NFCSP services.

To determine which characteristics were significantly associated with Chosen Child status, we compared group mean percentages and scores between the Definitely True Chosen Child group and the Definitely False ("DFCC")

group. We hypothesized that these two groups would be most likely to encompass caregivers who were certain about their status as Chosen Child or non-Chosen Child. T-test, Chi-square, and Mantel-Haenszel chi-square statistics were used to test significant differences between the two groups. Significance was set at  $p < 0.05$ .

We examined the following characteristics:

- **Caregiver demographics (9 items):** Annual household income levels; lives in urban or rural location; employment status; education level; marital status; age; gender; race/ethnicity; and hospital or emergency department visit in past 6 months.
- **Caregiving-related characteristics (11 items):** Years of caregiving; cares for another older adult; cares for children; daily caregiving intensity (measured by caregiver-reported activities of daily living (ADL) assistance frequency); weekly caregiving hours; if caregiving is financially difficult or not; caregiver out-of-pocket expenditures; caregiver confidence; satisfaction of caregiving; if caregiver feels appreciated by CR; and lives with CR.
- **Care recipient characteristics (4 items):** If CR has Alzheimer's disease or related dementias (ADRD); if the CR argues a lot; CR gender; and CR age.
- **Caregiver support (6 items):** Has someone to help; use of caregiver educational services by NFCSP and/or any organization; number of respite hours received by NFCSP; any organization, family and/or friends; use of NFCSP caregiver supplemental services such as transportation, home modifications, and medical equipment; perception of unmet need for caregiving; and, among NFCSP users only, the perception that the services definitely helped them continue caregiving.
- **Caregiver well-being (6 items):** Self-reported caregiver burden score (measured by 4-item Zarit Burden Inventory); perception that caregiving is emotionally difficult; self-rated physical health; self-rated quality of life; self-rated level of fatigue; and self-reported frequency of emotional distress. The last four items are from the validated Patient-Reported Outcomes Measurement Information System (PROMIS) Short Forms for Global Mental Health and Global Physical Health (version 1.1): quality of life, frequency of emotional distress, level of fatigue, and physical health.<sup>27</sup> These items use a 5-point scale that allows for the calculation of group mean scores.

## RESULTS

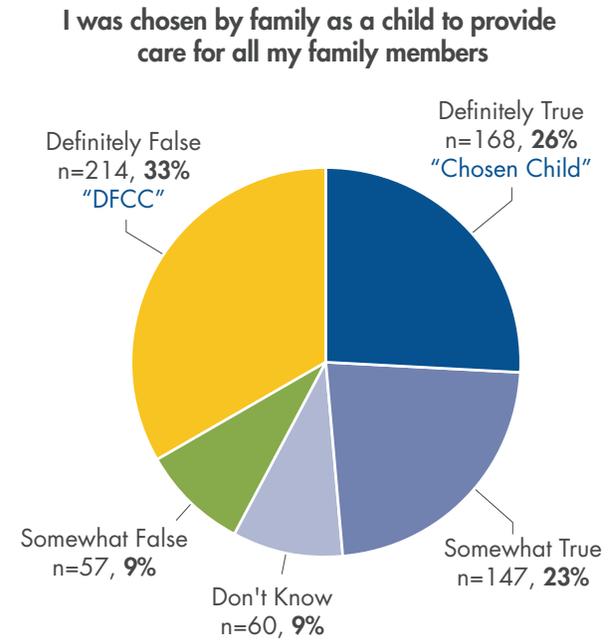
Among the full sample of 646 child caregivers, daughters (81%) represented the majority. The distribution by caregiver race was 63% White, 19% Black, 13% Hispanic, and 5% other race, including Asian (n=13), Hawaiian (n=2), American Indian (n=5), and Other (n=19). The mean age of the caregivers was 59 and the mean age of the CRs was 85. On average, child caregivers had been caregiving for their CR for 6 ½ years. Fifty-two percent of the CRs were diagnosed with Alzheimer’s Disease or related dementias (ADRD).

As shown in Figure 1, the response frequencies to the Chosen Child survey item were 33% Definitely False (“DFCC”), 9% Somewhat False, 23% Somewhat True, and 26% Definitely True Chosen Child.

### Chosen Child by Gender and Race

The full sample of child caregivers were 523 females and 123 males. The gender-specific prevalence of Chosen Child were not statistically different: 27% of the females and 23% of the males responded Definitely True. Using four categories of race, as shown in Table 1, White and Black caregivers had lower reported prevalence of Chosen Child status (25% for both) than Hispanic caregivers and other racial/ethnic caregivers (31% for both). However, these differences were not statistically significant.

**Figure 1:** Response frequencies to the Chosen Child survey item (n=646)



**Table 1.** Chosen Child item response prevalence by caregiver race

Response Frequencies Among Each Race Category					
Response Category	White (n=404)	Black (n=122)	Hispanic (n=81)	Other (n=39)	All (n=646)
Definitely True: Chosen Child	25%	25%	31%	31%	26%
Other	41%	41%	43%	33%	41%
Definitely False: DFCC	34%	34%	26%	36%	33%
Total	100%	100%	100%	100%	100%

## Chosen Child Use of NFCSP Caregiver Services

Among the 510 child caregivers who were asked if they used NFCSP educational services in the past 6 months, the percent who said “yes” by response group were: 24% of Chosen Child, 25% of Somewhat True, 21% of Don’t Know, 19% of Somewhat False, and 20% of DFCC. The same 510 caregivers were asked if they used NFCSP respite care in the past 6 months, and the percent who said “yes” by response group were: 40% of Chosen Child, 50% of Somewhat True, 47% of Don’t Know, 33% of Somewhat False, and 42% of DFCC. The use percentages for both services were not significantly different across groups. Lastly, among those who used NFCSP respite care, the number of respite hours per

week did not significantly vary by group, with 8 hours for Chosen Child, 9 hours for Somewhat true, 10 hours for Do not know, 7 hours for Somewhat false, and 8 hours for DFCC.

## Characteristics Associated With the Chosen Child Caregiver

Among the 36 characteristics analyzed, we found significant differences between Chosen Child and DFCC caregivers for five characteristics: 1) Annual household income, 2) Employment status, 3) Received respite care from family or friends, 4) Perception that NFCSP services enable longer caregiving, and 5) Frequency of emotional distress. The results for the five characteristics are shown in Table 2.

**Table 2.** Characteristics that significantly differed between Definitely True Chosen Child caregivers (N=168) and Definitely False Chosen Child (DFCC) caregivers (N=214)

Characteristic / Survey Item	Chosen Child % Yes or Mean	DFCC % Yes or Mean	p-value
<b>Caregiver Annual Household Income &lt;=40K annually.</b> <i>Item:</i> During the last year what was your total household income before taxes from all sources, including Veterans benefits, Social Security, and other government programs? <i>Values:</i> Yes or No (based on income range selected by respondent)	60.7%	48.6%	0.018
<b>Employment status.</b> <i>Item:</i> Are you currently employed full or part time? <i>Values:</i> Yes or No	39.3%	52.3%	0.009
<b>Received respite care from family or friends.</b> <i>Item:</i> In the past 6 months, have you received respite care from a family member, friend, neighbor, or other volunteers? <i>Values:</i> Yes or No	40.1%	53.5%	0.009
<b>Perception that NFCSP services enables longer caregiving.*</b> <i>Item:</i> Have the services you received enabled you to provide care longer than would have been possible without these services? <i>Values:</i> Yes = Definitely yes; No = all other responses including probably yes, probably not, and definitely not	51.6%	39.3%	0.035
<b>Frequency of Emotional Distress</b> <i>Item:</i> In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?" <i>Values:</i> 1=never; 2=rarely; 3=sometimes; 4=often; 5= always	2.68	2.38	0.009

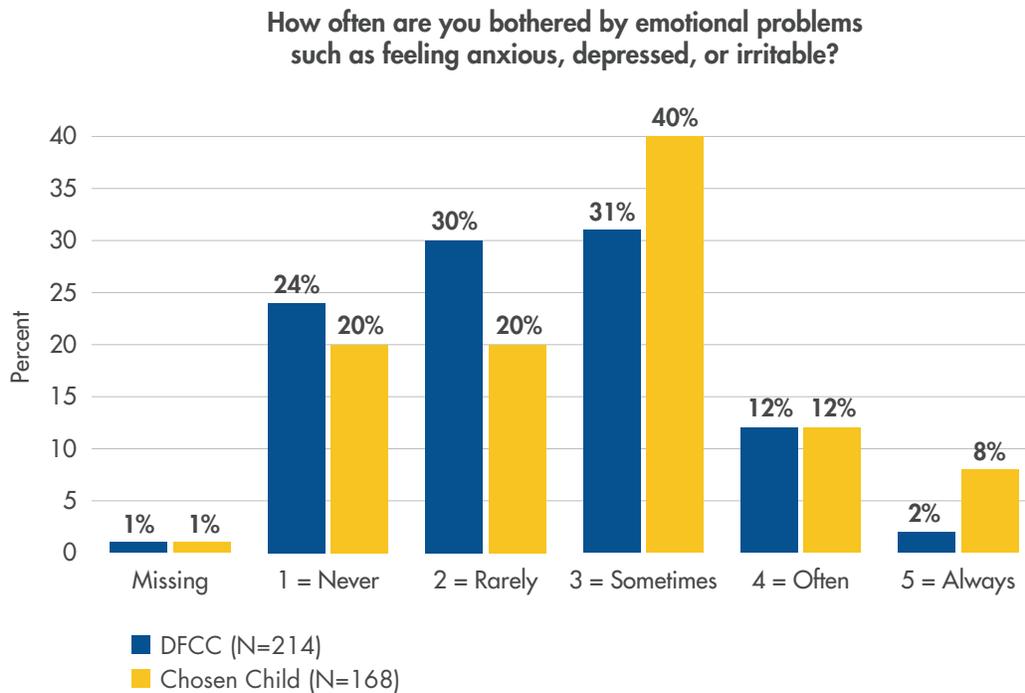
\* The number of caregivers who used services from the National Family Caregiver Support Program (NFCSP) in the past 6 months and was asked this item was 124 from the Chosen Child group and 173 from the DFCC group.

In comparison to DFCC caregivers, the Chosen Child caregivers reported lower income, less employment, less respite care from family or friends, a greater sense of effectiveness for NFCSP services, and more frequent emotional distress.

A closer look at the emotional distress responses show that 8% of Chosen Child caregivers reported that they were always bothered by emotional problems compared to only 2% of the DFCC caregivers, and 40% of Chosen Child caregivers reported that they were never or rarely bothered by emotional problems compared to 54% of the DFCC caregivers. (See Figure 2.)



**Figure 2.** Frequency of emotional distress between Definitely False Chosen Child (DFCC) caregivers and Chosen Child



As shown in Table 3, the unadjusted mean emotional distress score for DFCC (2.38) was significantly lower than the unadjusted mean score for Chosen Child (2.68). We tested to see if this difference remained significant after controlling for risk factors and protective factors of emotional distress found in the literature.<sup>28,29</sup>

We controlled for caregiver employment status, self-reported physical health, self-reported caregiver burden, and caregiving daily intensity.<sup>30</sup> After adjusting for these potential confounders, the mean scores for DFCC (2.43) and Chosen Child (2.64) remained significantly different.

**Table 3.** Mean scores for Emotional Distress by Chosen Child group

Chosen Child Response	N	%	Mean of Emotional Distress Frequency	
			Unadjusted Mean	Adjusted Mean*
Definitely False (DFCC)**	214	33.13	2.38	2.43
Somewhat False	57	8.82	2.53	2.53
Don't Know	60	9.29	2.58	2.46
Somewhat True	147	22.76	2.59	2.61
Definitely True: Chosen Child**	168	26.01	2.68	2.64

\* Mean scores adjusted for caregiver employed or not, self-reported physical health, self-reported caregiver burden, and caregiving daily intensity.

\*\* Significantly different at  $p < 0.05$ .

## DISCUSSION

### Caregiver Employment, Education, and Income

Our exploratory analysis found that a little over one-third of the Chosen Child caregivers were employed, compared to roughly half of the DFCC caregivers. These are striking differences among two groups of preretirement-age child caregivers with a mean age of 59 years for both groups. Coincidentally, a higher percentage of Chosen Child caregivers reported an annual household income of \$40,000 or below in comparison to DFCC caregivers. However, the percentage of Chosen Child with a college degree (32%) or any education past high school (71%) was not significantly different than the percentage of DFCCs with a college degree (39%) or any education past high school (73%).

### Receipt of Respite Care

Although the Chosen Child caregivers and DFCC caregivers reported similar use of NFCSP respite care (40.3% and 42.1%, respectively), the Chosen Child caregivers reported receiving less respite care support from family, friends, neighbors, or other volunteers than DFCC caregivers (40.1% and 53.5%, respectively). It is possible that the Chosen Child with a high sense of familism and/or desire to manage and provide care for their elder relative on their own is less willing or struggles to ask a relative or friend to stay with the CR when they need a break.<sup>12,31</sup> Although not a statistically significant difference, the Chosen Child caregivers also reported less respite care support from other organizations (including Medicare and Medicaid) in comparison to DFCC caregivers (15.0% and 22.9%, respectively).

## Perception of NFCSP Helpfulness

A significantly higher percent of Chosen Child caregivers than DFCC caregivers responded with “Definitely yes” when asked if the NFCSP services enabled him or her to provide care longer (51.6% and 39.3%, respectively). Thus, when support was received, it appears that the majority of Chosen Child caregivers perceive the support to be helpful. (This question in the survey was about NFCSP services in general and not specific to educational services or respite care.)

## Care Recipient Characteristics, Caregiving Dynamics, and Caregiver Burden

The percentage of CRs with ADRD was not significantly different between the Chosen Child and DFCC caregiver groups (56.0% and 49.5%, respectively). Each group also reported similar caregiving intensity, caregiving hours per week, if they felt appreciated by CR, level of satisfaction from being a caregiver, self-reported physical health, and if they were receiving all the help they need. Lastly, the Chosen Child caregivers did not report higher levels of caregiver burden. On a scale from 1-5, with 5 representing the most burden, Chosen Child caregivers reported a mean burden score of 2.8 and DFCC caregivers reported a mean score of 2.7. These similar levels of self-reported burden are in line with findings from Losada et al. (2010), which suggest that familism does not affect emotional distress through burden, but through rigid and unrealistic beliefs about caregiving that are maladaptive to active coping.<sup>29</sup>

## Caregiving Emotionally Difficult and Emotional Distress

When asked “How emotionally difficult would you say that caring for CR is for you?” there were no significant differences in rates of response between Chosen Child caregivers and DFCC caregivers. This question was specific to emotional problems associated with caregiving. Yet, when asked about emotional problems without mention of caregiving, the Chosen Child caregivers reported experiencing emotional problems such as feeling anxious, depressed or irritable more often compared to the DFCC caregivers. After controlling for other factors related to emotional distress, the adjusted mean score for emotional distress for the Chosen Child caregivers (2.64) remained significantly higher (i.e., caregivers reported more frequently feeling distress) than the DFCC caregivers (2.43).

These findings align closely with existing literature on the association between familism and increased depression and anxiety among caregivers. However, one limitation to this cross-sectional analysis of caregivers was the inability to determine if the higher levels of emotional distress among the Chosen Child group were also prevalent before the commencement of caregiving. Another limitation was that, when interviewed, caregivers were not asked about their motivation for caregiving or their coping styles. This information would help to gain a deeper understanding of the emotional distress results.

## CONCLUSION AND IMPLICATIONS

Among a sample of adult caregivers who are the children of their care recipients, one-fourth identified as the person in their family who was chosen at an early age to provide care to family members. Our analysis found that the characteristics associated with Chosen Child caregivers were lower annual household income, less employment, less respite care received from family and friends, higher perception that NFCSP services enable them to care longer, and more frequent emotional distress.

Family and friends should be aware that the Chosen Child caregiver may be hesitant to ask for respite care or other types of support and, thus, they should not

assume that their help is not needed in caring for the caregiver's parent or any other family member. Support organizations and health care providers can assist Chosen Child caregivers by encouraging involvement from multiple family members as an avenue for additional support.

Individuals performing caregiver assessments should ask caregivers about their motivation for caregiving to identify those who may be at risk for negative outcomes associated with familism. Interventions for the Chosen Child caregiver should focus on active coping strategies such as planning, seeking help, and positive mindsets to help improve the Chosen Child's emotional health.

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