

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

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## ABSTRACT

**Background and Objective:** Family caregivers who have been chosen by their family for the caregiving role may be under a unique type of stress due to familism and/or lack of choice. The purpose of this exploratory analysis was to investigate the characteristics of family caregivers who self-identified as the “Chosen Child” caregiver.

**Methods:** We used survey data from 652 child caregivers collected in December 2016 as part of the outcome evaluation of the National Family Caregiver Support Program (NFCSP). We compared the characteristics between the caregivers who responded “definitely true” when asked if they were chosen by their family as a child to provide care (“Chosen Child”) and the caregivers who answered “definitely false” to chosen child (DFCC).

**Results:** Compared to DFCC caregivers ( $n=214$ ), Chosen Child caregivers ( $n=168$ ) experienced emotional distress more often ( $p=0.009$ ), were more likely to have annual household income  $\leq$ \$40,000 ( $p=0.018$ ), were less likely to be employed ( $p=0.009$ ), and were less likely to have received respite care in the past 6 months from family or friends ( $p=0.009$ ). The mean emotional distress score remained significantly different between Chosen Child and DFCC caregivers after adjusting for potential confounders (2.64 vs. 2.43, respectively).

**Conclusion:** Family and friends should be aware that the Chosen Child caregiver may be at risk for emotional distress and may be hesitant to ask for respite care or other types of support. Interventions for the Chosen Child should help them seek support when needed.

**Keywords:** caregiver distress, informal caregiving, caregiver support

## **El niño o la niña elegidos: características de los cuidadores familiares seleccionados a una edad temprana para cuidar a sus padres**

### RESUMEN

**Antecedentes y objetivo:** Los cuidadores familiares que han sido elegidos por su familia para el rol de cuidador pueden estar bajo un tipo único de estrés debido al familiarismo y/o la falta de elección. El propósito de este análisis exploratorio fue investigar las características de los cuidadores familiares que se autoidentificaron como el cuidador del “Niño Elegido”.

**Métodos:** Utilizamos datos de encuestas de 652 cuidadores de niños recopilados en diciembre de 2016 como parte de la evaluación de resultados del Programa Nacional de Apoyo a Cuidadores Familiares (NFCSP). Comparamos las características entre los cuidadores que respondieron “definitivamente cierto” cuando se les preguntó si fueron elegidos por su familia cuando eran niños para brindar cuidado (“Niño elegido”) y los cuidadores que respondieron “definitivamente falso” al niño elegido (DFCC).

**Resultados:** En comparación con los cuidadores de DFCC (n=214), los cuidadores de niños elegidos (n=168) experimentaron angustia emocional con más frecuencia (p=0,009), tenían más probabilidades de tener un ingreso familiar anual  $\leq$ \$40 000 (p=0,018), tenían menos probabilidades de ser empleados (p=0,009), y tenían menos probabilidades de haber recibido cuidados de relevo en los últimos 6 meses de familiares o amigos (p=0,009). La puntuación media de angustia emocional siguió siendo significativamente diferente entre los cuidadores de Chosen Child y DFCC después de ajustar los posibles factores de confusión (2,64 frente a 2,43, respectivamente).

**Conclusión:** Los familiares y amigos deben ser conscientes de que el cuidador del niño elegido puede estar en riesgo de sufrir angus-

tia emocional y puede dudar en solicitar cuidados de relevo u otros tipos de apoyo. Las intervenciones para el Niño Elegido deberían ayudarlo a buscar apoyo cuando sea necesario.

**Palabras clave:** angustia del cuidador, cuidado informal, apoyo del cuidador

## 被选中的孩子：儿童时期被选为照顾父母的家庭照顾者的特征

### 摘要

**背景和目标：**由家庭指定承担照顾角色的家庭照顾者可能由于家庭主义和/或缺乏选择而遭受独特的压力。本探究性分析旨在研究自我认定为“被选中的孩子”的家庭照顾者的特征。

**方法：**我们使用652名儿童照顾者的调查数据，该数据收集于2016年12月并作为国家家庭照顾者支持计划（NFCSP）成果评价的一部分。我们比较了当被问及是否在儿童时期被家人选择提供护理时回答“绝对正确”的照顾者（“被选中的孩子”）和对此回答“绝对错误”的照顾者（DFCC）的特征。

**结果：**与DFCC照顾者（n=214）相比，“被选中的孩子”照顾者（n=168）经历情感痛苦的频率更高（ $p=0.009$ ），家庭年收入 $\leq 40,000$ 美元的可能性更大（ $p=0.018$ ），不太可能被雇用（ $p=0.009$ ），并且在过去6个月内从家人或朋友那里得到临时托护的可能性较小（ $p=0.009$ ）。在调整了潜在的干扰因素后，“被选中的孩子”和DFCC照顾者的平均情感痛苦评分仍然存在显著差异（分别为2.64和2.43）。

**结论：**家人和朋友应该意识到，“被选中的孩子”照顾者可能有情感痛苦的风险，并且可能不愿寻求临时托护或其他类型的支持。对“被选中的孩子”的干预措施应帮助其在需要时寻求支持。

**关键词：**照顾者的痛苦，非正式照顾，照顾者支持

## Introduction

The family caregiver is a relative, spouse, partner, or friend who provides care and support to someone at home without pay. The family caregiver assumes a critical role in caring for older Americans living at home, and is a vital component of long-term care (National Academies of Sciences, Engineering, and Medicine, 2016). The family caregiver helps their family member—most often a spouse or parent—with activities of daily living, health care activities, and complex medical/nursing tasks (Sorrell, 2014; Wolff et al., 2016). The replacement of family caregivers, who care for millions of older adults and people with disabilities in America, with paid services could cost up to \$470 billion a year (Reinhard, Feinberg, et al., 2019).

Estimates from the year 2020 indicate that approximately 41.8 million Americans have provided unpaid care to an adult age 50 or older in the prior 12 months, representing approximately a quarter of households in the United States (AARP & National Alliance for Caregiving, 2020). While taking care of an adult family member can be a source of joy and fulfillment, for many caregivers it is also associated with considerable stress, depression, anxiety, social isolation, and burden, which can compromise the caregiver's mental health and physical health (Adelman et al. 2014; Judge et al., 2011; Schulz & Sherwood, 2008).

## *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 (Mendez-Luck et al., 2016). Pearlin's caregiver stress and coping model considers people's beliefs to be an important influence on their mental health (Pearlin, 1994). 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 (Mendez-Luck et al., 2016). For example, Cox (2013) found that familism has a positive influence on caregiver well-being when the caregiver perceives that the family is a strong source of support. However, other caregiver studies have found familism to be associated with higher levels of depression, more emotional distress, and poorer subjective physical health (Del-Pino-Casado et al., 2017; Rozario & DeRienzi, 2008).

When emotionally distressed or burdened by caregiving, caregivers can attempt to improve their quality of life through various coping strategies (Greenglass, 2002; Rodríguez-Pérez et al., 2017). For example, an active coping strategy includes attempts to solve or modify problems through planning, acceptance, and help-seeking (Del-Pino-Casado et al., 2011; Pérez-Cruz et al., 2019). Receiving respite care, so-

cial 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 (Clay et al., 2008; Del Pino et al., 2011; Sorrell, 2014; Vandepitte et al., 2016). 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 (Carver et al., 1998; Rozario & DeRienzi, 2008). 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 (Kim et al., 2007; Sayegh & Knight, 2010).

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 (Schulz et al., 2012; Winter et al., 2010). Sayegh and Knight (2010) found that a significant proportion of familism's unfavorable effect on caregiver outcomes was due to feelings of obligation. 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 primary health condition, and demographics. 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 ac-

cept the role out of a sense of family obligation or duty (Dilworth-Anderson et al., 2004; Vandepitte et al., 2016) which may not be equally distributed across the family. 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 (Winter et al., 2010).

Our study uses self-reported data to identify "Chosen Child" caregivers—who may have had little choice in assuming the role of caring for a parent—and to explore the caregiver characteristics associated with "Chosen Child" in comparison to other child caregivers.

## **Data and Methods**

Survey data were collected in December 2016 from a random sample of family caregivers across the nation who were participants in the Administration for Community Living's outcome evaluation of the National Family Caregiver Support Program (NFCSP) (Westat, 2018). The NFCSP is a federal program designed to support family caregivers by providing caregiver education and training, individual counseling, information about available services, and support groups to help caregivers better manage their responsibilities and to help cope with the stress of caregiving. The NFCSP also provides respite care either at home or at adult day care facilities, so that caregivers can rest or attend to their own needs.

To identify a sample of NFCSP clients, the sample design for the evaluation was based on a two-stage stratified probability sample of Area Agencies on Aging (AAA) clients who were listed as recipients of NFCSP services. The first stage was a stratified sample of 316 AAAs across the nation and the second stage consisted of a systematic random sampling of NFCSP clients within the sampled AAAs. The NFCSP evaluation's study sample consisted of 1,568 caregivers. The caregivers' relationships to care recipients were 43% spouse ( $n=678$ ), 42% child ( $n=652$ ), 2% in-law child ( $n=37$ ), and 13% other, including grandchildren and friends ( $n=201$ ).

We used survey data collected from caregivers who were caring for a parent. In other words, they were the care recipients' children. 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.

### *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 amongst their family. 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." Response options were defi-

nitely true, somewhat true, somewhat false, and definitely false. The caregivers that responded "Definitely true" were categorized as Chosen Child and those that responded "Definitely false" were categorized as Definitely False Chosen Child (DFCC). We chose the caregivers who answered the extreme responses to the question because we wanted to compare caregivers who were certain about their status as Chosen Child or non-Chosen Child.

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 who received any NFCSP service. 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.

### *Caregiver Characteristics*

The survey collected the basic demographics of each caregiver such as their annual household income level category, if the caregiver lives in an urban or rural location, if the caregiver was currently employed (either full or part-time), educational attainment level, marital status, age, gender, and race ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, other). We hypothesized that the Chosen Child in comparison to DFCC would have

lower income, less education, and be of minority race (Falzarano et al., 2021).

The survey also asked several questions related to a caregiver's situation. Therefore, we examined items from the survey that best measured the intensity of the caregiving role (Bastawrous et al., 2015). We compared how many years the caregiver had been caregiving, their care recipient's age, if the caregiver cares for another older adult, if the caregiver also cares for children, the daily intensity level (ranging from 0-5 with 5 being the highest) was measured by the caregiver reporting the frequency of helping their care recipient with activities of daily living (ADL). Also collected were the caregivers' weekly caregiving hours, if the caregiver thought caregiving was financially difficult or not, the caregivers' self-reported confidence level of caregiving, the caregiver's satisfaction of caregiving, if the caregiver felt appreciated by the care recipient, and if the caregiver lived with their care recipient. We hypothesized that the Chosen Child caregivers would report more confidence in caregiving than the DFCC caregivers (Falzarano et al., 2021).

Lastly, we explored whether the Chosen Child group was more or less likely to be caring for a parent with Alzheimer's disease or related dementias (ADRD) and if they reported that their care recipient argues a lot with him or her.

### **Support with Caregiving**

The survey had many items that asked about the caregiver support they re-

ceive. More specifically, we explored responses to the following items: use of caregiver educational services by NFCSP and/or any organization; use of NFCSP caregiver supplemental services such as transportation, home modifications, and medical equipment; number of respite hours received by NFCSP, any organization, family and/ or friends; perception of unmet need for caregiving; and, among NFCSP users only ( $n=510$ ), the perception that the services definitely helped them continue caregiving.

### **Caregiver Well-Being**

The survey measured a caregiver's perception that caregiving is emotionally difficult, caregiver burden, caregiver mental health and caregiver physical health. Burden was measured using the short Zarit Burden Inventory (Bedard et al., 2001; Zarit et al., 1980), which included four items designed to assess different aspects of caregiver burden: (a) not having sufficient time for self, (b) feeling stressed between caregiving and other responsibilities, (c) feeling strained when around the care recipient, and (d) feeling uncertain about what to do about the care recipient. The overall burden score from the set ranged from 1-5 with 5 representing the greatest burden. Perception that caregiving is emotionally difficult was asked with this question: "How emotionally difficult would you say that caring for care recipient is for you?" The response options were 1=not at all difficult, 2=a little, 3=somewhat, and 4=very difficult.

The survey also included four

items 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 (Hays et al., 2009). Each of the PROMIS items use a 5-point response scale. For example, “How would you rate your physical health?” had response options of 1=poor, 2=fair, 3=good, 4=very good, and 5=excellent. The question “In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?” had response options of 1=never, 2=rarely, 3=sometimes, 4=often, and 5=always. This last question is the item that we label “emotional distress.”

## Analysis

To determine which characteristics collected in the survey were significantly associated with Chosen Child status, we compared group mean percentages and scores between the Chosen Child group and the DFCC group. T-test, Chi-square, and Mantel-Haenszel chi-square statistics were used to test significant differences at  $p < 0.05$  between the two groups.

### *Adjusted Mean of Emotional Distress*

We performed a sensitivity analysis on the emotional distress mean scores of all five groups of child caregivers. We tested to see if the group mean scores were significantly different after controlling

for confounders that could influence emotional distress (Del-Pino-Casado et al., 2019; Del-Pino-Casado et al., 2015). More specifically, for this analysis, we performed a regression model to adjust the mean scores by employment status, rate of physical health, Zarit burden score, and caregiving daily intensity.

## Results

The full sample of child caregivers were 523 females and 123 males. Eighty-one percent were the care recipient’s daughter. 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 care recipients was 85. On average, child caregivers had been caregiving for their parent for 6 ½ years. Fifty two percent of the care recipients 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.

### *Race and Gender of Chosen Child*

Table 1 presents the distribution of child caregivers by race. Twenty-five percent of the White and Black caregivers were Chosen Child and 31% of Hispanic caregivers and other racial/ethnic caregivers were Chosen Child. These



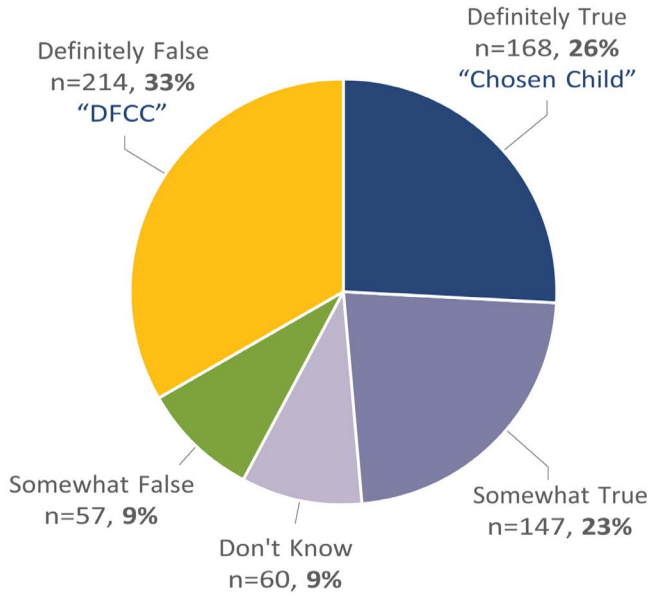


Figure 1: Response frequencies to the Chosen Child survey item “I was chosen by family as a child to provide care for all my family members” (n=646)

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%

frequencies did not differ significantly across race categories. Twenty-seven percent of the women were Chosen Child and 23% of the males were Chosen Child. The gender frequencies were also not statistically significant.

### Use of NFCSP Caregiver Services

Because some of the child caregivers in the full had not used NFCSP services,

there were 510 child caregivers who used any NFCSP service. Among them, the percent who used any NFCSP educational services in the past 6 months were: 24% of Chosen Child, 25% of Somewhat True, 21% of Don't Know, 19% of Somewhat False, and 20% of DFCC. The percent who used NFCSP respite care in the past 6 months were: 40% of Chosen Child, 50% of Some-

what True, 47% of Don't Know, 33% of Somewhat False, and 42% of DFCC. The use percentages for these two services were not significantly different across groups. Lastly, among those who used NFCSP respite care, the mean 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***

Our analysis shows that, among all the survey items analyzed, there were five characteristics that differed significantly between Chosen Child and DFCC caregivers. In comparison to DFCC caregivers, on average, the Chosen Child caregivers were 1) more likely to have an annual household income  $\leq$  \$40,000 (60.7% vs. 48.6%;  $p = 0.018$ ), 2) less likely to be employed (39.3% vs. 52.3%;  $p=0.009$ ), 3) less likely to have received respite care from family or friends (40.1% vs. 53.5%;  $p=0.009$ ), 4) more likely to say that NFCSP services enabled them to be a caregiver longer (51.6% vs 39.3%;  $p=0.35$ ), and 5) more often bothered by emotional distress (a score of 2.68 vs. 2.38;  $p=0.009$ ). The results for the five characteristics are shown in Table 2.

### **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.

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). After adjusting for caregiver employment status, self-reported physical health, self-reported caregiver burden, and caregiving daily intensity, the mean emotional distress scores remained significantly different between the Chosen Child (2.64) and the DFCC (2.43). The regression model's fit as measured by adjusted r-square was 0.3521. The significant parameters in the regression model to calculate adjusted means were Chosen child group (0.054,  $p= 0.0092$ ), Employed (-0.17,  $p=0.0137$ ), Self-rated Physical Health (-0.23,  $p <.0001$ ); Zarit burden mean score (0.61,  $p <.0001$ ); and Caregiving daily intensity = (-0.04,  $p= 0.0345$ ).

To understand these scores as they relate to a caregivers' daily situation, Figure 2 shows that the 8% of Chosen Child caregivers reported that they were always bothered by emo-

**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
<p><b>Caregiver Annual Household Income &lt;=40K annually.</b></p> <p><b>Item:</b> 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: Yes or No (based on income range selected by respondent)</i></p>	60.7%	48.6%	0.018
<p><b>Employment status.</b></p> <p><b>Item:</b> Are you currently employed full or part time? <i>Values: Yes or No</i></p>	39.3%	52.3%	0.009
<p><b>Received respite care from family or friends.</b></p> <p><b>Item:</b> In the past 6 months, have you received respite care from a family member, friend, neighbor, or other volunteers? <i>Values: Yes or No</i></p>	40.1%	53.5%	0.009
<p><b>Perception that NFCSP services enables longer caregiving.*</b></p> <p><b>Item:</b> Have the services you received enabled you to provide care longer than would have been possible without these services? <i>Values: Yes = Definitely yes; No = all other responses including probably yes, probably not, and definitely not</i></p>	51.6%	39.3%	0.035
<p><b>Frequency of Emotional Distress.</b></p> <p><b>Item:</b> In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable? <i>Values: 1=never; 2=rarely; 3=sometimes; 4=often; 5=always</i></p>	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 were asked this item was 124 from the Chosen Child group and 173 from the DFCC group.

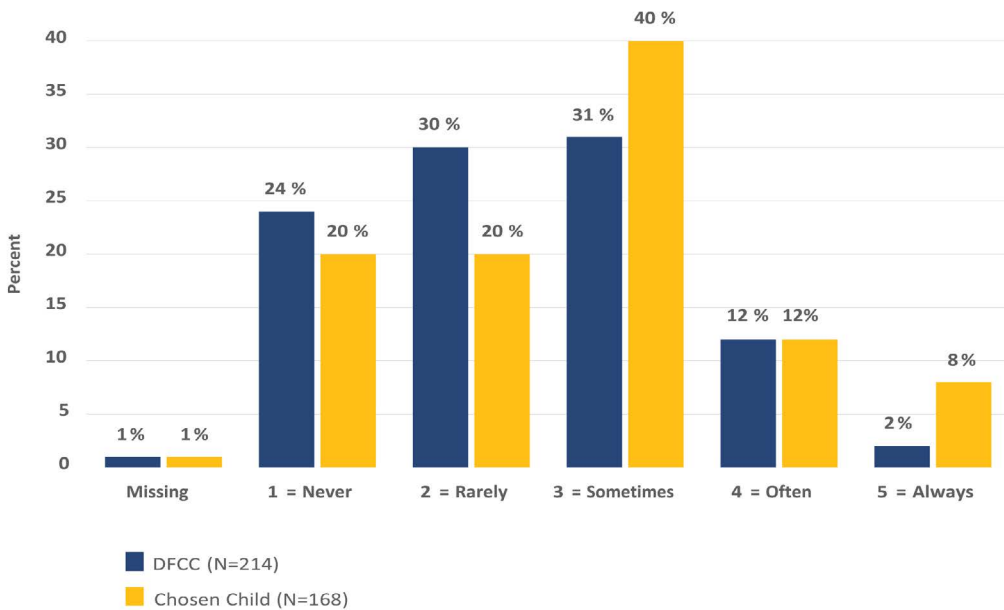
**Table 3.** Mean scores for Emotional Distress by Chosen Child group

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.

\*\* The DFCC's adjusted mean significantly different ( $p < 0.05$ ) from Chosen Child's adjusted mean.

**Response frequency to “How often are you bothered by emotional problems such as feeling anxious, depressed, or irritable?”**



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

tional problems compared to 2% of the DFCC caregivers. Clinically, more than half of the Chosen Child caregivers (60%) felt bothered sometimes, often, or always by emotional problems such as feeling anxious, depressed, or irritable. In comparison, less than half of the DFCC caregivers (45%) felt bothered sometimes, often, or always by emotional problems due to these feelings.

### **Caregiver Support**

When comparing Chosen Child to DFCC, there were 124 Chosen Child caregivers and 173 DFCC caregivers who used NFCSP services in the past 6 months. 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;  $p=0.009$ ). The Chosen Child caregivers also reported less respite care support (not significantly different) from other organizations including Medicare and Medicaid in comparison to DFCC caregivers (15.0% and 22.9%, respectively).

Lastly, 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%). Interestingly, we found no difference in gender or race/ethnicity between the Chosen Child and DFCC groups. Both groups had a mean age of 59 years.

### **Discussion**

**O**ur analysis found evidence that there are family caregivers who felt chosen by their family as a child to be the caregiver to their parent(s). Surprisingly, this phenomenon was found equally across race/ethnicity and gender. We also did not find that the Chosen Child caregiver had higher levels of self-reported confidence in caregiving.

The Chosen Child caregivers reported receiving less respite support from family, friends, and non-NFCSP organizations. These results support previous findings that link familism with caregivers not receiving the potential support available from family members (Mendez-Luck et al., 2016). 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 care recipient when they need a break due to avoidance coping (Sayegh & Knight, 2010).

Although we hypothesized less employment among the Chosen Child caregivers than the DFCC caregivers, we found the difference striking (39% vs. 52%, respectively). However, there was no difference in their responses to the financial difficulty of caregiving, although, as hypothesized, the Chosen Child caregivers had lower annual incomes than the DFCC caregivers. This is an interesting finding that needs exploration. Additionally, more research is needed to understand if the Chosen

Child's knowledge of their future obligation during young adulthood had an effect on career choice.

Caregiver burden was not higher for the Chosen Child. This finding aligns 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. Additionally, Crist et al. (2007) found that familism was not related to caregiving burden among Mexican American caregivers.

Furthermore, 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, distressed, depressed or irritable more often compared to the DFCC caregivers. These findings support previous studies that found that caregivers without choice are at higher risk for depression and anxiety (Schulz et al., 2012) and that caregivers with low levels of social support or respite care from family and friends are more frequently distressed (Falzarano et al., 2021).

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 caregiver educational services or respite care.) It is unclear why the DFCC group responded less favorably to this item about NFCSP services enabling longer caregiving, especially because this group may have been less prepared for their caregiving role. A limitation to this question is that it asked about all the NFCSP services the caregiver had received and, thus, the caregivers were responding to varying levels of support.

## **Limitations**

**D**ue to the cross-sectional nature of this analysis, we were unable to determine if Chosen Child caregivers had higher levels of emotional distress and less employment than DFCC caregivers before the commencement of caregiving. Future research on Chosen Child caregivers should include longitudinal studies to gain a deeper understanding of the mental health of the caregivers and the effects of increasing caregiver support on their well-being. Another limitation is that our study does not have any measures of coping. More specifically, caregivers were not asked about their motivation for caregiving (to determine if they really lacked choice) or their coping levels or styles (Romero-Moreno et al., 2011). In addition, the p-values for

multiple tests were not adjusted, potentially resulting in an increased possibility of type 1 error and chance findings.

## **Implications**

**S**upport organizations and health care providers can assist Chosen Child caregivers by encouraging involvement from multiple family members as an avenue for additional support either physically, emotionally, or financially. 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. Support groups, education, and training 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. Furthermore, community support services must also be aware that the risk of unmet caregiver needs, burden, and emotional stress of non-White caregivers could be heightened due to language and/or cultural barriers and the impact of the COVID-19 pandemic (Greenwood et al., 2015; Li, 2004; Potter, 2018; Campione & Zebrak, 2020; Longacre et al., 2021).

Since 2014, legislation at the State and Federal level have brought more attention to the role of the family caregiver. The majority of States have enacted the Caregiver Advise, Record, Enable (CARE) Act which requires the identification of a patient's caregiver during hospitalization and the integration of the caregiver in the discharge

process. Furthermore, while there is variability to how each State adopts the CARE Act, another key element is for the hospital staff to perform an assessment of the caregiver's capacity to provide the post-acute home care (Reinhard, Young, et al., 2019). During the assessment of the caregiver's capacity and needs, providers should remind caregivers to seek support from their family and friends. Furthermore, if additional family is in attendance, the clinicians should take this opportunity to help families identify and validate the caregiver's needs (Chi, Demiris, Lewis, Walker, & Langer, 2016).

The medical field, social workers, and caregiver support programs should be aware of how familism and a child caregiver's lack of choice when caring for a parent can negatively affect their well-being and their ability to ask for help. While all can agree that care plans for an elderly patient need to be family-centered, the assessment of the caregiver by a healthcare, clinical, or social service professional may be just as important (Kelly, Wolfe, Gibson, & Feinberg, 2013). These professionals should be trained to identify the child caregiver who did not choose their role and/or feel obligated through familism, and thus may be suffering from a unique type of emotional distress. Once identified, the Chosen Child may need to be counseled about avoidance coping and should be encouraged to seek social support and respite care.

Lastly, in addition to improving the coordination of federal programs and activities that support family caregivers through the National Family

Caregiving Strategy (RAISE Council, 2021), new state and federal policies and programs for family caregiver compensation beyond those offered by Medicaid and the Veterans Affairs are needed, especially for the child caregiver who can no longer work, or has to cut back work hours due to caregiving.

## Conclusion

Using data collected from caregivers across the nation, we found that among a sample of child caregivers, one-fourth identified themselves as the person in their family

who was chosen at an early age to provide care to their parents. 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.

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