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1 **Sociodemographic disparities in adult-child informal caregiving intensity in the US:**
2 **Results from the new National Study of Caregiving**

3

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8

9 **Abstract:** Nearly 60 million informal caregivers provide care to aging adults. Despite its many
10 benefits, high intensity caregiving can impact caregiver health and quality-of-life. Therefore, the
11 objective of our study was to assess socioeconomic and demographic disparities in caregiving
12 intensity among informal caregivers. Using a randomized, nationally representative database of
13 1014 informal offspring caregivers from Medicare enrollment databases, the associations between
14 informal caregiving intensity and age, race/ethnicity, and income were examined using binary and
15 ordinal logistic regression. Caregiving intensity varied by demographics. High ADL caregiving was
16 highest among Black, non-Hispanic caregivers. High IADL caregiving and high number of hours
17 spent caregiving was highest in females, and non-White caregivers. Although the overall association
18 between caregiving intensity and income was not significant, when stratified by race/ethnicity, this
19 association was positive for White caregivers and negative for non-White caregivers. Health care
20 providers frequently interact with informal caregivers and should be aware of trends in caregiving
21 and the needs and supports available to ameliorate caregiver burden. In order to protect caregivers,
22 policies and programs designed to promote wellbeing and mitigate the potential harms of
23 caregiving to health should consider these findings.

24

25 **Introduction:**

26 Over 34 million American adults have provided informal care to an adult over the age of 50
27 within the last 12 months, 47% of whom were caring for a parent (National Alliance for Caregiving,
28 2015). These figures are only expected to rise as the number of Americans over 65 years of age
29 grows from 47.5 million in 2015 to 98 million by 2060 (Administration on Aging, 2016). Informal
30 caregiving, the unpaid care and support family members and friends voluntarily provide to
31 individuals who are unable to function independently, has numerous benefits to care recipients and
32 society as a whole. These include savings to the national economy, prevention of hospitalization
33 and institutionalization, and allowing older residents to remain in their own homes (Chari, Engberg,
34 Ray, & Mehrotra, 2015). Informal caregivers are estimated to have spent over 30 billion hours a
35 year providing care to disabled or chronically ill individuals, with an opportunity cost savings of
36 \$522 billion per year that would otherwise be spent on formal care and institutionalization (Chari,
37 Engberg, Ray, & Mehrotra, 2015).

38 Despite these benefits of informal caregiving to the care recipient and to the national
39 economy, numerous negative effects associated with caregiving have been well documented in the
40 literature. Many studies have demonstrated the negative impacts on caregiver health-related
41 quality of life, including physical and emotional health consequences, that can occur as a result of
42 providing care, such as anxiety and depression (Cannuscio, et al., 2002; Ho, Chan, Woo, Chong, &
43 Sham, 2009; Macneil et al., 2010; National Alliance for Caregiving, 2015; Pinquart & Sorensen,
44 2011; Schultz & Sherwood, 2008). These negative health-related quality of life outcomes are
45 commonly referred to as caregiver stress, strain, or burden. Moreover, informal caregivers
46 providing a high amount of care may be particularly vulnerable to the effects of caregiver strain,
47 and may differ in substantial ways from those providing less care, such as their employment status,
48 the type of caregiving duties they provide, and the impact caregiving has on them (Jacobs, Laporte,
49 Van Houtven, & Coyte, 2014; National Alliance for Caregiving, 2015). The duties caregivers provide

50 may vary by sociodemographic factors, including race and gender, where female and non-white
51 caregivers were more likely to provide higher amounts of informal care than their counterparts
52 (National Alliance for Caregiving, 2015). However findings are mixed. Few studies have examined
53 differences in caregiving intensity by socioeconomic and demographic factors using a nationally
54 representative dataset.

55 There is a critical need to better understand who is providing informal care to aging
56 parents, and how to best provide the support, assistance, and resources caregivers may need. To
57 further the understanding of who is providing informal care, the objectives of this study were to
58 examine the demographic profile of informal adult-child caregivers in the U.S., and to assess the
59 sociodemographic differences in caregiving duties (caregiving “intensity”) among this population of
60 informal caregivers.

61

62 **Methods:**

63 *Study population*

64 The data were obtained from the 2011 National Study of Caregiving (NSOC) dataset, a
65 nationally representative sample of informal caregivers. The NSOC identified caregivers of National
66 Health and Aging Trends Study (NHATS) participants who were receiving assistance in self-care,
67 mobility, medical, or household activities. These caregivers were then contacted to participate in a
68 one-time, cross-sectional assessment of caregiving that included questions on caregiving activities,
69 duration, intensity, and demographics. This analysis focused on adult children caregivers to older
70 adult parents (n = 1014), a subset of informal caregivers.

71 *Outcome variables: Caregiving intensity*

72 Four individual measures of caregiving duties that are most common in the literature were
73 used to assess caregiving intensity: 1) Number of Activities of Daily Living (ADLs) performed, 2)
74 Number of Instrumental Activities of Daily Living (IADLs) performed, 3) Hours of caregiving

75 provided per month, and 4) Duration (years) of caregiving. To measure these four intensity
76 domains, items from the NSOC questionnaire assessing aspects of caregiver duties were used. ADLs
77 refer to daily self-care activities that are necessary for fundamental functioning. This was measured
78 by the number of personal care activities caregivers helped with each month, including eating,
79 bathing, dressing, toileting, and helping care recipient move around. IADLs consist of other
80 caregiving activities not necessary for fundamental functioning, but allow an individual to live
81 independently. This domain included the number of instrumental activities caregivers helped their
82 parent with, including medication management, scheduling medical appointments, and other health
83 and hygiene-related tasks. The last two intensity domains were calculated based on the average
84 number of hours spent caregiving in the last month, and average number of years providing care.
85 The top quartile (25%) of each individual intensity domain were considered 'High Intensity
86 Caregivers', while the bottom 75% were considered 'Low Intensity Caregivers'.

87 To calculate the composite intensity measure, each of the four individual measures of
88 caregiving intensity scored one point if considered 'high intensity', and zero points if considered
89 "low intensity". This composite score ranged from zero (provided no high intensity care in any of
90 the four individual caregiving measures) to four (provided high intensity care in all four individual
91 caregiver domains).

92 *Exposure variables: Caregiver demographics*

93 Four demographic characteristics of caregiver respondents identified in previous studies of
94 caregiving intensity were assessed, to include caregiver age, gender, race/ethnicity, and annual
95 household income (Navaie-Waliser, Spriggs, & Feldman, 2002; Navaie-Waliser, et al, 2002;
96 Fredman, Doros, Ensrud, Hochberg, & Cauley, 2009; Cohen, Cook, Sando, Brown, & Longo, 2017).
97 Demographic age was categorized into 10-year age groups (< 45, 45-54, 55-64, and 65+).
98 Race/ethnicity was based on three calculated domains (non-Hispanic White, non-Hispanic Black,
99 and 'Other' (Hispanic, American Indian, Native Hawaiian, Pacific Island, other non-Hispanic)).

100 Income was grouped into four \$25,000 intervals (\leq \$24,999, \$25,000-\$49,999, \$50,000-\$74,999,
101 and \$75,000 or more).

102 *Additional demographic confounders and covariates*

103 Other key confounders and covariates commonly used in studies of disparities in caregiver
104 intensity and are shown to affect caregiver intensity, including caregiver marital status (Brody,
105 Litvin, Hoffman, & Kleban, 1995; Dentinger & Clarkberg, 2002), presence of a child (under 18) living
106 in the home (Cohen, Cook, Sando, Brown, & Longo, 2017; Grundy & Henretta, 2006), and caregiver
107 co-resident status (care recipient and caregiver reside in same home) (Tennstedt, Crawford, &
108 McKinlay, 1993) were also assessed.

109 *Data analysis*

110 Univariate and bivariate analyses were used for all primary outcome and exposure
111 variables to assess individual measures of high intensity caregiving. For the composite measure of
112 high intensity caregiving, ordinal logistic regression models were used to calculate adjusted odds
113 ratios and 95% confidence intervals (CI), adjusting for covariates. Pairwise deletion was used to
114 handle missing values for each model. SAS 9.3 (Cary, NC) was used for all analyses.

115

116 **Results:**

117 *Demographics of NSOC adult-child caregivers*

118 The demographic breakdown for this sample of adult children caregivers is found in Table
119 1. The average age of caregivers was 54.6 years old. Sixty-nine percent of respondents were female,
120 while 31% were male. Respondents reported an average annual income of \$56,582. Sixty percent of
121 respondents identified as non-Hispanic White, 31% as non-Hispanic Black, and 9% as another
122 racial/ethnic group. Adult children caregivers spent an average of 85 hours a month providing care,
123 and had been caring for an elderly parent for 5.6 years.

124 *Individual measures of Caregiving Intensity*

125 High ADL caregiving was most prevalent in caregivers aged 45-54 (28.1%) and non-
126 Hispanic Black caregivers (33.9%). High IADL caregiving was significantly higher in females
127 (30.3%) than in males (20.6%). Compared to White caregivers, high IADL caregiving was
128 significantly higher among non-Hispanic Black caregivers (33.5%) and caregivers of 'other'
129 racial/ethnic groups (30.9%). A high number of hours spent caregiving was highest in females
130 (27.9%), non-Hispanic Black caregivers (36.1%) and 'other' race/ethnicities (30.8%), and
131 individuals earning less than \$25,000 per year (37.6%). High years of caregiving was highest in
132 non-Hispanic Black caregivers (33.8%) and caregivers of 'other' race/ethnicities (35.7%). All
133 results are displayed in Table 2.

134 *Composite measure of caregiving intensity*

135 Differences in high intensity caregiving varied by gender, race, and other sociodemographic
136 factors (Figure 1). Female caregivers had higher odds of providing high intensity care than their
137 male caregiver counterparts (OR = 1.43, CI [1.03, 1.99]). The odds of providing high intensity
138 caregiving was greater for non-White caregivers (caregivers of Black and 'other' race/ethnicities)
139 than White caregivers (OR = 1.86, CI [1.30, 2.64]). Co-resident caregivers were more likely to have
140 provided high intensity caregiving than caregivers not residing with their care recipient (OR = 1.70,
141 CI [1.19, 2.42]). Additionally, a negative association between annual income and high intensity
142 caregiving was observed: as caregivers' annual income decreased, the odds of providing high
143 intensity caregiving significantly increased ($p < 0.001$).

144

145 **Discussion:**

146 This study sought to better understand who is providing high intensity informal care to an
147 older parent. Our findings indicate that there are notable differences in caregiving intensity that
148 vary by caregiver socioeconomic and demographic factors. High intensity caregiving was most
149 prevalent among females, non-White caregivers, those living with their care recipient, and low

150 income caregivers. These results are in line with previous studies that report greater caregiving
151 responsibilities among females, racial/ethnic minorities, shared co-residence, and low income
152 caregivers (Kim, Chang, Rose & Kim, 2012; Pinqart & Sörensen, 2005; National Alliance for
153 Caregiving, 2015). However, the observed associations were dependent on the type of care being
154 provided, such that certain caregivers were more likely to provide high intensity care in some
155 domains of caregiving than others. Surprisingly, no differences were observed between males and
156 females in high ADL caregiving. Historically, this has not been the case, and could be a result of the
157 changing face of informal caregivers, or in how the caregivers were selected for inclusion in this
158 sample.

159 While our results largely confirm previous findings, our analysis adds to the current body of
160 caregiver research in several ways. First, the analysis uses a nationally representative sample of
161 caregivers previously identified by their care recipient. This is an important distinction from other
162 representative samples where respondents self-identify as caregivers. Second, our focus on adult
163 child caregivers sheds light on who is providing high intensity care to an aging parent. Investigating
164 adult child caregivers – an important and large subset of caregivers – is important, as they differ
165 from other types of caregivers (i.e. spousal) in significant ways. Examining this group separately is
166 recommended, as significant differences in caregiver characteristics, needs, and burden have been
167 noted (Chappell, Dujela & Smith, 2014; Pinqart & Sörensen, 2011). Third, this analysis compares
168 caregivers based on the level of care they provided (high vs. low intensity).

169 Caregiving intensity, whether measured by the type or amount of assistance provided is
170 associated with various health effects and quality of life outcomes (Shultz & Sherwood, 2008).
171 Numerous studies have shown any type of informal caregiving can result in negative physical and
172 emotional health consequences for the caregiver, often referred to as caregiving-related stress or
173 burden (Cannuscio, et al., 2002; Ho, Chan, Woo, Chong, & Sham, 2009; Macneil et al., 2010; National
174 Alliance for Caregiving, 2015; Pinqart & Sörensen, 2011; Schultz & Sherwood, 2008). With noted

175 differences in the intensity of care being provided, we anticipate implications for caregiver health
176 and quality of life that also vary by sociodemographics. Research suggests that differences exist in
177 caregiver quality of life among male and female caregivers, caregivers of different racial and ethnic
178 groups, ages (Neugaard, Andresen, McKune & Jamoom, 2008; Anderson et al., 2013; Covinsky,
179 2003), and income levels (Williams, Forbes, Mitchell, Essar & Corbett, 2003).

180 Health care professionals should be aware of trends in high intensity caregiving among
181 informal caregivers providing high intensity care to an older parent. Gerontological nurses may
182 have frequent contact with aging adults and their informal caregivers who are susceptible to or
183 exhibiting signs of burnout and quality of life concerns. Their role in facilitative informal caregiving
184 has expanded from being primary caregivers to teaching and assisting family members to provide
185 care (Schulz & Sherwood, 2008). Nurses that provide informal caregivers a temporary break from
186 their caregiving responsibilities can significantly improve caregiver health and quality of life
187 (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012) and reduce subsequent caregiver burden
188 (Horton-Deutsch, Farran, Choi, & Fogg, 2002).

189 This group of health providers are especially poised to recognize symptoms of distress and
190 burnout, and offer appropriate resources for caregivers in need of additional supports. Such
191 support is facilitated through communication between nurses and informal caregivers, building
192 relationships with informal caregivers, and creating a culture of trust with the family of the care
193 recipient (Weman & Fagerberg, 2006). However, the availability of healthcare providers trained to
194 provide such support may depend upon the services and resources that are available at the local
195 level and may not be equitable for all informal caregiver populations throughout the US.

196 *Limitations:*

197 When interpreting these findings, there are a few important limitations to note. First, due to
198 the cross-sectional nature of this study, we are unable to determine causal relationships between
199 caregiver demographics and high intensity caregiving. A second wave of NSOC data will be available

200 within the year and future analyses may be able to determine causality. Second, we did not look at
201 caregiver employment, which may impact caregivers' ability to provide different types and levels of
202 care. Third, caregiving responsibilities was dichotomized into high and low caregiving intensity,
203 rather than assessed along a gradient. As such, a composite analysis was conducted to assess
204 overall caregiving intensity as a continuous measure composed of multiple types of caregiving (e.g.
205 ADLs, IADLs, and hours per month). Next, all measures were self-reported, which may bias the
206 results toward more socially acceptable responses to the measures examined in the study. Sample
207 weights were not used in the analysis, as the importance of including weights in regression models
208 such as these in which descriptive population parameters are not being estimated are a subject of
209 debate in the survey analysis literature. Lastly, we assumed that missing data were missing at
210 random, and therefore did not impute missing values, and instead handled the issue of missing
211 values through the use of pairwise deletion.

212

213 **Conclusions:**

214 Our findings show both females and non-White caregivers are more likely to provide high
215 intensity care, though the intersection between these two constructs and the influence on outcomes
216 is not well known. What remains to be seen is the impact sociodemographic interactions have on
217 caregiver intensity and caregiver health outcomes. In addition, as the number of aging adults
218 increase and the face of caregiving evolves, we anticipate the sociodemographics of caregivers
219 providing high intensity care will also change over time, as well as their needs and necessary
220 supports. Consequently, policies and programs designed to promote caregiver health and quality of
221 life should consider these important sociodemographic disparities to protect and support this vital
222 component of the US health care system.

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