



## Research Paper

## Differences in physical health, and health behaviors between family caregivers of children with and without disabilities



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## ABSTRACT

*Background:* Providing care for children with disabilities can negatively influence the physical health and health behaviors of family caregivers.

*Objectives/hypothesis:* The study purposes were to compare the prevalence of chronic conditions and health risk behaviors of family caregivers of children with and without disabilities and to examine associations between disability status of children and family caregivers' chronic conditions and health risk behaviors.

*Methods:* This study compared chronic conditions and health risk behaviors across adult family caregivers of children with a disability (FCG-D) and family caregivers of children without a disability (FCG) living in a U.S. household using 2015 National Health Interview Survey data. Health risk behaviors were defined as heavy drinking, current smoking, physical inactivity, and unhealthy sleep. Multivariable logistic regression was conducted to compare chronic conditions and health risk behaviors between FCG-D and FCG with adjustments for demographic and healthcare coverage covariates.

*Results:* FCG-D showed significantly greater likelihoods of chronic conditions (e.g., asthma, back pain, chronic bronchitis, heart conditions, migraine, and obesity) than FCG. FCG-D also exhibited significantly more smoking and unhealthy sleep.

*Conclusions:* Family caregivers of children with a disability reported significantly greater likelihoods of various chronic conditions and were more likely to engage in health risk behaviors (smoking and unhealthy sleep). Further study is needed to develop intervention programs for encouraging effective health-promoting behaviors among family caregivers of children with a disability as well as health policies for decreasing health disparities experienced by this population.

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In 2010, children with disabilities made up an estimated 7.94% of the U.S. population, and the overall prevalence of disability among children has increased 15.6% over the past decade.<sup>1</sup> Approximately 25% of all American families include a child with a disability.<sup>2</sup> Medical advances, shorter hospital stays, and expansion of home care technology have imposed higher care responsibilities for families, who are being asked to shoulder greater care burdens for longer periods of time.<sup>3</sup> Indeed, a National Alliance for Caregivers executive report estimated that approximately 3.7 million American caregivers have provided unpaid care to a child.<sup>4</sup> The health

and well-being of children are inextricably linked to their caregivers' physical, emotional, and social health; social circumstances; and child-rearing practices.<sup>5</sup> As such, more research on the health of caregivers of children with disabilities is warranted.

Research suggests that caring for children with disabilities can be a stressful responsibility, often negatively impacting the health of family caregivers.<sup>6</sup> Studies consistently report higher levels of psychological health problems including higher levels of perceived stress,<sup>7</sup> depression and lower levels of subjective well-being among caregivers of children with disabilities.<sup>8</sup> However, most of the research performed to date on the health of parents of children with disabilities has focused on psychological health with little attention to physical health outcomes. Among the few studies of family caregivers of children with disabilities, these caregivers have been found to have poorer physical health outcomes than family

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caregivers of typically developing children. For example, studies showed that parents having children with disabilities reported a greater variety and a greater overall number of chronic conditions<sup>9</sup> and a higher number of physical health complaints<sup>7</sup> compared to parents of typically developing children.

The demands of parenting children with disabilities may not only cause families' health problems but may also change their health risk behaviors. Because family caregivers of children with disabilities spend so much time in providing care, they may have little time or energy to engage in healthy lifestyle,<sup>10</sup> and thus their own physical and/or mental health may be compromised. Although large scale surveillance research is scarce, evidence does support that caregivers are vulnerable to high rates of health risk behaviors. In one of the few studies examining this topic, mothers of children with disabilities have been found to exhibit frequent sleep disruption activity due to night-time care responsibilities and low participation in leisure<sup>11</sup> and planned exercise programs.<sup>10</sup>

Most children with disabilities are cared for at home by their family caregivers, and the features of the family household affect both the well-being of the families and the risks they face. Even though household structure is highly variable across disability households, differences in socioeconomic status have been noted between families of children with and without disabilities. In general, caregivers of children with disabilities have been found to be more likely to be older, female, poorer, less employed, and covered by Medicaid.<sup>9,12–14</sup> As many studies have reported effects of lower socioeconomic status on a wide array of health indicators,<sup>15,16</sup> socioeconomic and demographic factors should be controlled for when comparing the impact of household disability status on family caregivers' health outcomes.

While a few diagnosis-specific differences exist, caregivers of children with any chronic condition experience similar impacts, concerns, and needs for support.<sup>17,18</sup> Thus, it is also necessary to examine the impact of children's disability status on family caregivers' health across a broad range of disabilities in children. A growing body of research suggests that family caregivers of children with disabilities have poorer health outcomes than caregivers of typically developing children. However, no American studies of family caregivers of children with disabilities have used a nationally representative sample to examine an extensive array of higher-risk chronic conditions or have examined the prevalence of a variety of health risk behaviors. The specific aims of this study were to (1) compare the prevalence of chronic conditions and health risk behaviors of family caregivers of children with and without disabilities and (2) examine associations between disability status of children and family caregivers' chronic conditions and health risk behaviors while controlling for covariates.

## Methods

### Data source

Data for this study was 2015 National Health Interview Survey (NHIS),<sup>19</sup> which employed cross-sectional, multistage area probability design sampling of non-institutionalized civilian individuals in the general U.S. population. NHIS is a household, questionnaire-based, in-person interview survey conducted annually by the National Center for Health Statistics of the Centers for Disease Control and Prevention. Households are selected through a stratified, randomized, probability-cluster design. Probability samples of the adult population in all 50 states and the District of Columbia are obtained. The survey data is maintained by the National Center for Health Statistics and provides cross-sectional health information. The final adult response rate for the 2015 NHIS was 55.2%.<sup>19,20</sup>

### Identification of children with a disability

Based on the person file of 2015 NHIS data, children with a disability were defined as children experiencing any activity limitations. A child was considered to have a disability if the survey respondent reported that the child experienced any of the following due to a chronic condition based on the criteria of Houtrow et al.(2014)<sup>1</sup>: limitations in the kinds or amounts of play activities done by other children (<5 years); needing help with personal care including bathing, dressing, eating, getting in and out of bed and chairs, using the toilet, and getting around the home (3 + years); difficulty walking without equipment (<18 years); difficulty remembering (<18 years); receipt of special education services or early intervention services (<18 years); or any other activity limitation (<18 years). The disability definitions used for children here conform with the International Classification of Functioning, Disability and Health Framework for understanding of disability.<sup>21</sup>

### Identification of caregivers living with children having disabilities

The 2015 NHIS dataset contained no information identifying primary caregivers of children with disabilities. Thus, for the 33,672 individuals included in the NHIS adult file, adult family caregivers are defined as adults 18 years and older who were living in a household with children with a disability and who identified themselves as family members of the children (FCG-D, n = 1436). Family caregivers were defined as adult family members living with children without disabilities (FCG, n = 8599). Adults without children were excluded from the study, as were adults who were not living in the same household with related children.

### Identification of physical health

To investigate the physical health outcomes of the FCG-D and FCG groups in this study, chronic conditions were selected based on a 2004 study by Brehaut et al.<sup>9</sup> that examined differences between family caregivers who had children with cerebral palsy and caregivers for typically developing children. Self-reported conditions were defined based on affirmative responses to the following question: "Have you ever been told by a doctor or health professional that you have [disease or condition]?" The chronic conditions included in this study were asthma, arthritis, back pain, cancer, chronic bronchitis, a cold in the past two weeks, diabetes mellitus, heart conditions (heart disease), high blood pressure (hypertension), joint symptoms, obesity, migraine/headaches, neck pain, sinusitis, stomach problems, and stroke. In addition to these chronic conditions, we included obesity, joint symptoms (including joint pain, aching, and stiffness), and neck pain. Obesity was defined as a body mass index (BMI) of 30 kg/m<sup>2</sup> or higher.<sup>22</sup>

### Identification of health risk behaviors

The health risk behaviors considered in this study were heavy drinking, current smoking, physical inactivity, and unhealthy sleep. Heavy drinking was defined as consuming 12 or more drinks in an entire life and as consuming more than 14 drinks per week in the past year for males and more than 7 drinks per week in the past year for females.<sup>23</sup> Current smoking was defined based on whether respondents were or were not currently smoking. Physical inactivity was defined based on the 2008 Physical Activity Guidelines for Americans; this guideline recommended that adults perform at least 150 min per week of moderate-intensity or 75 min per week of vigorous-intensity aerobic physical activity or an equivalent combination of moderate- and vigorous-intensity activity along

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