# The Impact of Caregiving for Children with Epilepsy, Down Syndrome, and Muscular Dystrophy on Informal Caregivers

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# Abstract

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**Objective**

While caregivers of children with chronic conditions are known to experience lower quality of life compared to caregivers of healthy children, there is limited research examining the impact of caregiving for children with specific conditions. The objective of this study is to compare how different demographic and clinical characteristics affect caregiver quality of life indicators among caregivers of children with epilepsy, Down syndrome, and muscular dystrophy.

**Methods**

Secondary analyses using data from a cross-sectional study that surveyed a national sample of caregivers (n=699). Linear regression models with interaction were used to test the effects of child diagnosis on caregiver stress and caregiver benefit with different moderating variables (caregiver hours, condition severity, number of child comorbidities, and caregiver resilience). A logistic regression model was used to examine the association between child diagnosis and job status change, and a linear regression model was used to determine how job status change impacts the relationship between caregiver stress and anxiety and the relationship between caregiver stress and depression.

**Results**

Caregivers who experienced a job status change reported higher mean depression (p=<0.001) and anxiety (p=<0.001) scores. When controlling for condition severity, caregivers of children with epilepsy reported higher mean stress scores (p=<0.001) and were also more likely to experience a job status change (p=<0.001) in comparison to all other diagnostic groups. However, higher mean stress scores reported by caregivers of children with epilepsy were not associated with differences in dedicated weekly caregiver hours, number of child comorbidities, or caregiver resilience.

## Conclusions

Job status change and condition severity provide some foundation for understanding differences in stress and benefit of caregiving experienced by caregivers. However, more research is needed to understand what drives the differences in caregiver experience between caregivers of children with epilepsy, Down syndrome, and muscular dystrophy.

**Contents**

## Overview of caregiving in the United States

There are approximately 53.0 million adults in the United States that have provided unpaid care to an adult or a child in the past 12 months (AARP & National Alliance for Caregiving, 2020). This type of caregiving is defined as "informal" caregiving, as they are providing "unpaid assistance to family members who are unable to function independently" (Hopps et al., 2017). Most informal caregivers are female (75%) who dedicate more hours and complete more caregiving tasks compared to males (*Caregiver Statistics: Demographics*, 2019). Tasks range from providing assistance with transportation, medication management, and coordinating doctor's visits, to more intense duties such assisting with dressing and bathing (*Caregiver Statistics: Demographics*, 2019).

There are approximately 14.1 million informal caregivers who provide care to a child under the age of 18 with a medical, behavioral, or other condition or disability, and approximately 1 in 5 children have a chronic illness that affects their daily function (AARP & National Alliance for Caregiving, 2020; Blackwell et al., 2019). Chronic conditions include asthma, diabetes, mental health conditions, cancer, and others. Managing care for children with chronic conditions is challenging and often causes physical and mental stress on parents, who are the primary informal caregivers (Adib-Hajbaghery & Ahmadi, 2019). In this paper, the term "caregivers" will be used to refer to informal, not paid, caregivers of children with chronic conditions.

## The impact of caregiving

The relationship between caregiving for a relative with a chronic health condition and stress has long been established by previous research. *Caregiver burden* is defined as "the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning" (Toledano & Domínguez, 2019). Caregivers are at increased risk for depression, anxiety, fatigue, poor sleep, stress, and overall lower quality of life due to the various psychological and physical strains of caregiving (Grady & Rosenbaum, 2015; Javalkar et al., 2017).

According to the Family Caregiver Alliance, depressive symptoms occur more frequently among caregivers, as 40-70% of caregivers have clinically significant symptoms of depression (*Caregiver Health*, n.d.). These percentages reflect similar trends among caregivers of children with chronic conditions, as one study found that 49.1% and 31.8% suffer from severe and moderate depression respectively (Piran et al., 2017). In addition to depression, the emotional stress of caregiving is also frequently reported among caregivers, although this varies among different subgroups of caregivers (Grady & Rosenbaum, 2015; AARP & National Alliance for Caregiving, 2020). For example, female caregivers report higher emotional stress due to caregiving compared to male caregivers (AARP & National Alliance for Caregiving, 2020; Family Caregiver Alliance, 2019; Piran et al., 2017). Caregiver stress is also dependent on reported caregiver hours, as one study found that 49% of caregivers who provide 21+ hours of care rate their stress as "high" compared to 30% of those providing less than 20 or fewer hours of care (AARP & National Alliance for Caregiving, 2020).

While caregivers of children with chronic conditions experience similar emotional stress compared to caregivers caring for adults, caregivers of children with chronic conditions experience greater parental stress compared to caregivers of healthy children (Cousino & Hazen, 2013; National Alliance for Caregiving, 2009b). The added stressors of incorporating treatment routines into family life, shifts in parental responsibilities due to caregiving, as well as limited coping mechanisms are the primary factors that contribute to greater stress (Cousino & Hazen, 2013). Moreover, children with more severe chronic conditions may require greater assistance with basic activities of daily living (ADLs), which in turn leads to greater caregiver burden and stress (Javalkar et al., 2017; Longacre et al., 2016; Lyons et al., 2015).

In addition to condition severity, the number of comorbidities a patient has (i.e., conditions that are present at the same time) is also associated with an increased burden for caregivers (Duggleby et al., 2016; Valderas et al., 2009). In the United States, one in three of the 11.2 million children with chronic conditions have multiple comorbidities (Javalkar et al., 2017). While numerous challenges arise for caregivers caring for children with complex conditions, not all caregivers will experience the same type of caregiver burden. This is not only due to differences in the type of care provided, but due to how the caregiver is able to cope with their caregiving duties.

## Resilience and caregiving

The ability of a caregiver to thrive or cope in a stressful situation gives insight into how caregiver burden is mitigated in some and not others. The term “resilience” is used frequently to describe how well caregivers adapt to their caregiving duties. Resilience is defined as the capacity of an individual to overcome adversity, withstand stress or bounce back from traumatic events (Zhao, 2016). Across multiple studies, resilience has proven to have protective effects against stress and caregiver burden (Zhao, 2016). While resilience can help manage stress, caregiver burden can also impede caregiver resilience (Zhao, 2016). Socio-environmental factors play an integral role in preserving caregiver resilience, as family and social support as well as strong social networks have positive effects on resiliency (Joling et al., 2016; Kobiske & Bekhet, 2018; Rosa et al., 2017; Zhao, 2016). Being a male caregiver, living apart from those receiving care, and low caregiver burden are caregiver characteristics associated with greater caregiver resilience (Joling et al., 2016). As previously described, most caregivers of children with chronic conditions are female, take on higher levels of caregiving burden, and tend to live with the children they care for (National Alliance for Caregiving, 2009a). Therefore, resilience may be lower among caregivers of children with chronic conditions.

Most research exploring the concept of resilience and caregiving focuses on caregivers of adults with chronic conditions. A literature review conducted by Lin and colleagues is one of the few analyses examining the role of resilience among caregivers of children with chronic conditions (Lin et al, 2013). While their evaluation also confirmed the importance of social and professional support systems, it did not distinguish between different types of conditions (Lin et al, 2013). Caregiver resilience is likely influenced by differences in treatment routines and caregiver responsibilities, which will vary depending on the type of condition the child has (Cousino & Hazen, 2013). Therefore, assessing caregiver resilience for those caring for children with various chronic conditions is an essential next step for future research.

### Caregiving and employment

Most employed informal caregivers in the United States will experience a change in their employment status in order to be able to perform their caregiving duties. Difficulty balancing work and caregiving is a common experience among informal caregivers, and will often result in a loss of wages, health insurance, and job benefits (*Caregiver Statistics: Work and Caregiving*, 2020). Caregiver employment status is often dependent on the burden or intensity of caregiving (AARP & National Alliance for Caregiving, 2020; Longacre et al., 2016; National Alliance for Caregiving, 2009). One study found that 73% of caregivers with a high burden (those providing 48+ hours of care/week and providing assistance with at least 3 daily activities) had to make work accommodations in order to provide care, either by altering work hours, taking time off, taking a leave of absence, etc. (National Alliance for Caregiving, 2020). Female caregivers are more likely to make more drastic changes to their working status compared to their male counterparts, by reducing hours, taking a less demanding job, or leaving their job entirely (National Alliance for Caregiving, 2009a). In addition, caregivers who are unable to continue working experience stress due to the increase in time dedicated to caregiving, whereas employed caregivers report higher stress due to difficulties in navigating work accommodations (Longacre et al., 2016). These various stresses impact not only the long-term financial stability for working and non-working caregivers, but their overall quality of life (Longacre et al., 2016).

While understanding the relationship between stress, employment, and caregiving is necessary for developing a greater understanding of the complex caregiver experience, more research is needed to understand this relationship for caregivers of children with chronic conditions.

## Developing clinically meaningful and psychometrically sound scales to measure the impact of caregiving

Studies comparing the impact of caregiving for those caring for children with different chronic conditions have been hampered by a lack of universal, reliable, and valid measures that adequately assess caregiver impact. To address this measurement gap, Amtmann et al developed and tested the reliability and validity of two Item Response Theory based item banks: the University of Washington Caregiver Stress Scale (UW-CSS) and the University of Washington Caregiver Benefit Scale (UW-CBS) (Amtmann et al., 2020).

In their cross-sectional study, the items in the item banks were administered to caregivers of children under the age of 18 with epilepsy, Down syndrome and muscular dystrophy, as well as a community sample of caregivers throughout the United States (Amtmann et al., 2020). It should be noted that children with epilepsy had severe forms of the condition, and the majority of children with muscular dystrophy had a common form of the condition known as Duchenne muscular dystrophy (DMD) (Amtmann et al., 2020). In addition to the two measures, participants also answered questions related to their health, specific questions related to their quality of life, their child's condition, and basic demographic information (Amtmann et al., 2020). Children with these specific conditions were chosen because each condition involves a different type of disability (Amtmann et al., 2020). Children with muscular dystrophy develop progressive physical disabilities, and children with Down syndrome have intellectual disabilities. Children with epilepsy can develop both intellectual as well as physical disabilities. By including children with primarily physical or intellectual disabilities, or both disabilities, researchers were able to compare the impact on caregiver stress and benefit.

## **The impact of caregiving for children with epilepsy, muscular dystrophy, and Down syndrome**

As previously discussed, there is limited research aimed at exploring the impact of caregiving for children with different chronic conditions. This section reviews the literature on caregiving for children with epilepsy, Down syndrome, and muscular dystrophy, as these conditions will be the focus of analysis.

### **Children with epilepsy**

In 2015, 3 million adults and 470,000 children (age 0-17) were diagnosed with epilepsy, comprising 1.2% of the total US population (Russ et al., 2012; Zack & Kobau, 2017). Epilepsy is a chronic brain disorder that causes "recurrent episodes of sensory disturbance, loss of consciousness, or convulsions” (*Epilepsy: Meaning of Epilepsy by Lexico*, 2020). There are dozens of different types of epilepsy syndromes, with varying levels of severity (Holmes, 2008).

Most research examining the impact of caring for a child with epilepsy is focused on seizure burden, as the unpredictability of seizures, seizure frequency, and seizure-related injuries contributed to greater caregiver stress (Berg et al., 2019; Chiou & Hsieh, 2008). However, there is limited research targeting other issues that impact caregiving. One study found that providing transportation, patient care, and difficulty in arranging care were the primary challenges for caregivers of children with Dravet Syndrome, a rare and severe form of epilepsy (Campbell et al., 2018). Caregivers with lower quality-of-life scores were also more likely to report difficulty in managing their child’s behavior problems, provided greater assistance with physical functioning, and also had to leave their job due to caregiving (Campbell et al., 2018). While these results are valuable, it should be noted that the sample size was small (n=34) and included adults with Dravet Syndrome as well, not just children (Campbell et al., 2018).

Cognitive impairments are the most common comorbidities associated with epilepsy, and greatly impact intellectual development (Hamiwka & Wirrell, 2009; Kim & Ko, 2016). Developmental and intellectual disabilities, as well as mood and behavior issues, can range from mild to severe depending on type of syndrome present, age of onset, frequency of seizures, and how well the condition can be managed (Holmes, 2008). Children with epilepsy may experience other medical issues as well, as one study found that children with epilepsy were at greater risk for developing gastrointestinal disorders (such as malnutrition), musculoskeletal disorders, neurologic disorders (i.e., cerebral palsy), immune disorders, and others (Aaberg et al., 2016). While it is important to understand the different types of comorbidities associated with this condition, more research is needed to understand how these comorbidities impact caregiving.

## Children with Down syndrome

Down syndrome is a common chromosomal disorder, as about 6,000 babies are born with Down syndrome annually (*Data and Statistics on Down Syndrome*, 2019). Down syndrome is a lifelong condition that causes cognitive and developmental delays as well as learning disabilities ranging from mild to moderate (*Down Syndrome*, 2012). Roughly half of babies born with Down syndrome have a heart defect (congenital heart disease), and more than half will experience vision problems as well as hearing loss (*What Conditions or Disorders Are Commonly Associated with Down Syndrome?*, 2017). They are also at risk for developing hypothyroidism, digestive issues, and are more likely to have epilepsy (*Data and Statistics on Down Syndrome*, 2019; *Down Syndrome*, 2012).

There are very few current studies examining the impact of caregiving for children with Down syndrome. One 2006 study assessed caregiver health for caregivers of children with different disabilities, which included children with Down syndrome in addition to other conditions such as cerebral palsy, autism, and others (Murphy et al, 2007). While their results echoed similar issues previously discussed (i.e., caregivers experience greater stress and anxiety due to caregiving, negative impact on caregiver health, etc.), it is impossible to adequately assess the impact of caring for children with Down syndrome due to the inclusion of multiple conditions (Murphy et al., 2007).

Caregiver quality of life may be higher among caregivers of children with Down syndrome compared to children with other developmental disabilities. Caregivers of children with Down syndrome report lower levels of depression and stress compared to caregivers of children with other disabilities (i.e., autism) (Stoneman, 2007). Researchers speculated that differences in child behavior as well as greater caregiver social support may help explain these findings (Stoneman, 2007). More research is needed to determine other factors that contribute to lower levels of stress, as there may be differences in dedicated caregiver hours, caregiver job status, and condition severity.

## Children with Muscular Dystrophy

Muscular dystrophy is a progressive muscle disease caused by a genetic mutation (*Muscular Dystrophy: Definition of Muscular Dystrophy by Lexico*, 2020). There are several different types of muscular dystrophies, which can affect different muscle groups and vary in severity (*What Is Muscular Dystrophy?*, 2019). Duchenne muscular dystrophy (DMD, one of the most common forms of the disease) occurs in about 14 in 100,000 children, almost exclusively in males between age 5-24 (*What Is Muscular Dystrophy?*, 2019). Muscle weakness usually begins before age 5, and affects the arms, legs, and most children with DMD begin using a wheelchair around age 12. (*Diseases - DMD - Signs & Symptoms*, 2019; *What Is Muscular Dystrophy?*, 2019). A third of children with DMD will have a learning disability, but very few develop severe cognitive disabilities (*Diseases - DMD - Signs & Symptoms*, 2019).

Due to limitations in physical functioning, children with DMD require extensive care (Landfeldt et al., 2016). Children with DMD can also have other comorbidities, which include diminished heart, lung, and respiratory function as the disease progresses (Landfeldt et al., 2016; *What Are the Types of Muscular Dystrophy?*, 2016). Most caregivers stop working or reduce working hours in order to provide care (Landfeldt et al., 2016). While one study found that anxiety and depression were higher among caregivers of children with DMD compared to the general population, the majority of the caregivers in their sample also expressed positive aspects of caregiving despite the high level of caregiving demands (Landfeldt et al., 2016). Another study examining the impact of caring for children with neuromuscular disorders (including

DMD) showed no significant difference in parental stress compared to parents caring for healthy children (Mah et al., 2008). While investigators attributed this to adopting to caregiving demands over time, more research is needed to determine why some caregivers report less stress regardless of high caregiving demands (Mah et al., 2008).

To summarize, more research is needed to further understand the impact of caregiving for children with epilepsy, Down syndrome, and muscular dystrophy. In addition to confirming the reliability and validity of their two developed measures, Amtmann et al found that while caregivers of children with epilepsy, Down syndrome, and muscular dystrophy reported higher stress scores compared to the sample of community caregivers, caregivers of children with epilepsy reported the highest levels of stress (caregiver stress was defined as “negative impact of caregiving on the physical, social, and emotional lives of caregivers, including negative impact on the financial resources and time”) (Amtmann et al., 2020). While caregiver benefit did not differ significantly from the clinical sample, caregivers in community sample reported slightly higher benefit scores compared to the clinical sample (caregiver benefit was defined as “a positive impact on lives of caregivers, including appreciating important things in life and becoming a better person”) (Amtmann et al., 2020). Resilience was negatively correlated with stress (r=-0.35) and positively correlated with benefit (r=0.28) (Amtmann et al., 2020). Depression and anxiety were also positively correlated with stress (r=0.46 and r=0.52, respectively) and negatively correlated with benefit (r=-0.19 and r=-0.16, respectively).

The aim of this study is to further build on the findings of Amtmann et al (2020) and investigate different factors that may contribute to caregiver quality of life (i.e., employment status change due to caregiving, reported caregiver hours, disease severity, number of comorbidities, and caregiver resiliency) among caregivers of children with epilepsy, Down syndrome and muscular dystrophy. This analysis will provide a more thorough understanding of the caregiver experience and may inform future policies to address the impact of caregiving.

## Methods

A secondary data analysis was conducted using data collected by Amtman et al (2020) in order to examine the relationship between caregiver stress and employment status change, reported caregiver hours, disease severity, and comorbidities, as well as the relationship between caregiver resiliency and benefit. This analysis did not require Human Subjects Research review as it did not meet the federal definitions of human subject research. For a more detailed description of the methodology for the primary study, refer to Amtmann et al. (2020), and Jensen et al. (2017)

### Recruitment and survey administration

Study recruitment included a "clinical sample" of caregivers who provided care for children with epilepsy, Down syndrome, or muscular dystrophy and a "community sample" of caregivers who provided usual care for children with no specific diagnoses or health care needs. Recruitment materials were provided by study staff and distributed through physical flyers and through social media via various US advocacy organizations for families with children with epilepsy, Down syndrome and muscular dystrophy (including Rare Epilepsy Network (REN), Down Syndrome Consortium, and Parent Project Muscular Dystrophy). Caregivers from the community sample were recruited through a panel company (Op4G), or flyers, email, text messages, and social media posts. While the community sample included mostly healthy children, children with different chronic conditions were also included. Participants were offered up to $20 for completing an online survey via REDCap.

## Study participants

A total of 699 caregivers were included in this analysis. The clinical sample included 378 caregivers of children with epilepsy (n=123), Down syndrome (n=137), and muscular dystrophy (n=118). The community sample was recategorized into two samples: “healthy” (n=208) and “other condition” (n=113). Children with diabetes, hypertension, lupus, or other conditions were categorized into the other condition sample (see table A4.a. and A4.b. under appendix for full list of conditions). Children that did not have those conditions were categorized into the healthy sample. Caregivers caring for more than one child with the same condition (i.e., two children with epilepsy) or different conditions (i.e., one child with epilepsy and one child with Down syndrome) were excluded from analysis. Caregivers caring for children under these circumstances may experience unusually high levels of stress that would bias the analysis. One caregiver that reported dedicating over 600 weekly hours to caregiving was also omitted from analysis.

## Measures

Table 1 describes the measurement scales used in this study: The University of Washington Caregiver Stress Scale (UW-CSS) measured caregiver stress, which was defined as “negative impact of caregiving on the physical, social, and emotional lives of caregivers, including negative impact on the financial resources and time”) (Amtmann et al., 2020). The University of Washington Caregiver Benefit Scale (UW-CBS) measured caregiver benefit, which was defined as “a positive impact on lives of caregivers, including appreciating important things in life and becoming a better person”) (Amtmann et al., 2020). Caregiver depression was self-reported using the PROMIS depression scale, which assessed a caregiver’s sense of worthlessness, helplessness, hopelessness and if they felt depressed in the last seven days (*PROMIS–29 Profile* *v2.0.*, n.d.). Caregiver anxiety was reported using PROMIS anxiety scale, which assessed a caregiver's sense of fearfulness, worry, and uneasiness in the last seven days (*PROMIS–29 Profile v2.0.*, n.d.). The UW resilience score measured caregiver perceived resilience, which was defined as the capacity for caregivers to bounce back from and/or maintain function in the face of adversity (University of Washington Resilience Scale (UWRS) Version 1 Users Guide, 2017).

In addition to the above items, the following information was collected: socio-demographic characteristics (such as marital status, race, annual household income), job status change, total weekly hours dedicated to caregiving, and severity of the child's condition, and total number of child comorbidities. Job status change included the following categories: changing jobs, started working, quit job, laid off, taking family/medical leave, taking a leave of absence, increased hours or decreased hours due to caregiving. Weekly caregiver hours were self-reported by the caregiver. Condition severity was reported using mild, moderate, and severe options (categories mild and moderate were combined due to sample size restrictions). Each caregiver responded with "No" or "Yes" for the 25 listed comorbidities, and the total number of comorbidities was the sum of all confirmed comorbidities.

### *Scoring*

Data was scored by summing responses to all items and transforming the summary score into a T-score using the conversion table provided for each domain. Forms with no missing data can be scored using the look-up scoring tables provided in the designated user guides (Amtmann et al., 2020; *University of Washington Caregiver Benefit Scale (UW-CBS) Version 1 Users Guide*, 2017; *University of Washington Caregiver Stress Scale (UW-CSS) Version 1 Users Guide*, 2017; *University of Washington Resilience Scale (UWRS) Version 1 Users Guide*, 2017). If a form is missing one or two items, the score can be approximated by pro-rating the score ((raw total score

* total # of items in the short form)/# of items answered). Individuals missing more than two items were not scored for that domain as Item Response Theory (IRT) software such as IRTpro should be used to score the data. A higher T-score represents a higher level of that domain (i.e. higher caregiver stress T-score signifies a higher level of caregiver stress). All T-scores are a standardized score with a mean of 50 and a standard deviation (SD) of 10 for each domain.

### Analysis

Data was analyzed using STATA 13 software (*StataCorp, 2013*). In order to ensure accuracy of model estimates, residual errors were inspected for normality and homoskedasticity. Multicollinearity was also checked using variance inflation factors (VIF). Due to heteroskedasticity in the models, robust standard errors were used to ensure accurate estimates. Logistic regressions and liner regressions with interactions were used to test for significant differences in the effect of each moderator variable in each diagnostic group. Significance level was set at alpha = 0.05.

The primary research questions pertain to variables that affect parental stress (see research questions 1-4). Linear regression models with interaction terms were used to test the effects of child diagnosis on caregiver stress and/or caregiver benefit with different moderating variables (weekly caregiver hours, condition severity, number of child comorbidities, and caregiver resiliency). These moderating variables were included to assess whether they altered the relationship between child diagnosis and stress and/or benefit. The secondary research questions refer to variables that are the potential consequences of caregiving (job status change due to caregiving, depression, and anxiety) (see research questions 5-6). A logistic regression model was used to determine the association between child diagnosis and job status change, and a linear regression model was used to determine how job status change impacts the relationship between caregiver stress and anxiety and the relationship between caregiver stress and depression. Table 2.a and 2.b. present a complete list of models with analysis type and hypotheses ($H_1$- $H_6$).

The following research questions and hypotheses were developed for this analysis:

1) Is there a difference in reported caregiving hours for those that care for children with epilepsy compared to the other two conditions? Do caregiving hours moderate the relationship between child diagnosis and reported caregiving stress?
   $H_1$: Caregivers of children with epilepsy are more likely to report higher caregiving hours compared to children with muscular dystrophy and Down syndrome. Higher caregiver hours will lead to greater caregiver stress.

2) Does condition severity moderate the relationship between child diagnosis and reported caregiving stress?
   $H_2$: Caregivers of children with epilepsy are more likely to report greater condition severity compared to caregivers of children with Down syndrome and muscular dystrophy. There will be a statistically significant difference in reported stress scores among the different severity categories for each diagnostic group.

3) Does the number of child comorbidities impact the relationship between child diagnosis and reported caregiver stress?
   $H_3$: As the number of child comorbidities increases, caregiver stress will increase.

4) Does caregiver resiliency moderate the relationship between child diagnosis and reported caregiving stress and caregiver benefit?

$H_4$: The relationship between reported caregiver stress/benefit and resilience will be significantly different between the different diagnostic groups

5) Is there an association between a child's diagnosis and job status change?

   $H_5$: Caregivers of children with each of the three diagnosis are more likely to experience a job status change compared to the caregivers of healthy children.

6) How does job status change affect the relationship between stress and anxiety and stress and depression?

   $H_6$: Caregivers that report a job status change more likely to report higher levels of depression and anxiety.

## Results

### Caregiver stress, condition severity, and weekly caregiver hours

Caregivers of children with epilepsy reported the highest percentage of children with a severe condition (86.7%) compared to caregivers of children with Down syndrome (46.4%) and muscular dystrophy (17.8%) (see table A2 in the appendix). After adjusting for age, sex, race, and ethnicity, there was no statistically significant difference between the mean stress scores of caregivers with mild/moderate (m= 62.5) and severe (m=63.1) epilepsy (difference=0.56, 95% CI: -3.76-4.88, p=0.64). However, there was a statistically significant difference in mean stress scores between caregivers of children with mild/moderate (m=51.5) and severe Down syndrome (m=56.5) (difference=5.0, 95% CI: 2.38-7.66, p <0.001). There was also a statistically significant difference in mean stress between caregivers of children with mild (m=53.2) and severe (m=61.2) muscular dystrophy (difference=8.0, 95% CI: 4.77-11.18, p <0.001).

The main effect of child diagnosis on caregiver stress was also statistically significant regardless of severity level. Caregivers of children with epilepsy were statistically significantly different from caregivers of children with Down syndrome (difference=-8.9, 95% CI: -11.55- -6.21, p <0.001) and muscular dystrophy (difference=-5.7, 95% CI: -8.60- -2.80, p <0.001). There was also statistical difference in mean stress scores between caregivers of children with muscular dystrophy and Down syndrome (difference=3.2, CI: 1.08-5.30, p= 0.003) (see table 4).

Weekly caregiver hours was only reported by caregivers of children with epilepsy (m=80.4, SD=41.2), Down syndrome (m=77.5, SD=39.5), and muscular dystrophy (m=65.0, SD=40.2) (see table A1 in the appendix). For every additional hour of caregiving per week, mean stress scores increased by 0.01 points among caregivers of children with epilepsy. However, the effect of weekly caregiver hours was not statistically significant (95% CI: -0.02-.05, p= 0.38). The impact of caregiver hours on stress did not significantly differ between the diagnostic groups, indicating that the effect of caregiver hours on stress was consistent among caregivers of children with all three conditions. When examining the main effect of child diagnosis on caregiver stress, caregivers of children with Down syndrome reported statistically lower mean stress scores compared to caregivers of children with epilepsy (difference=-12.78, 95% CI: -19.06-6.50, p <0.001). Caregivers of children with muscular dystrophy also reported statistically lower mean stress scores compared to caregivers of children with epilepsy (difference=-11.92, 95% CI: -18.22-5.61, p <0.001) (see table 5).

### Caregiver stress, resilience, and child comorbidities

The effect of resilience on caregiver stress was statistically significant, as mean stress score decreased by 0.21 for every 1-point increase in resilience among caregivers of healthy children (95% CI: -0.33- -0.09, p=0.001). The effect of resilience on stress was also consistent across all diagnostic groups. Caregivers of children with epilepsy reported the highest total number of comorbidities (m=6.0, SD=2.2), followed by caregivers of children with Down syndrome (m=5.1, SD=2.4), caregivers of children with muscular dystrophy (m=3.5, SD=2.2), caregivers of children with other conditions (m=3.2, SD=2.1), and caregivers of healthy children (m=0.36, SD=0.83) (see table A1). When examining the effect of child comorbidities, for every additional comorbid condition, mean stress scores increased by 0.98 among caregivers of healthy children. However, the effect of the total number of comorbidities on mean stress scores was not significant (95% CI: -0.05-2.01, p=0.06), nor was there any diagnosis by comorbidity interaction. When examining the effect of child diagnosis on stress, there was only one statistically significant difference in mean stress scores between caregivers of children of epilepsy and caregivers of healthy children (difference=11.77, p =0.02, 95% CI: 2.13-21.41) (see table 6).

### Caregiver benefit and resilience

While there was no effect of age and ethnicity on caregiver benefit, female and African American caregivers reported statistically higher mean benefit scores compared to male (difference=4.40 , 95% CI: 2.46-6.33, p <0.001) and white (difference=3.63, 95% CI: 1.03-6.24, p=0.01) caregivers. Mean benefit scores increased by 0.31 points for every 1-point increase in resilience among caregivers of healthy children. This effect of resilience on caregiver benefit scores was statistically significant (95% CI: 0.20-0.43, p <0.001). However, there were no diagnosis by resiliency interactions, indicating that the effect of resiliency was consistent across all diagnostic groups (see table 7).

### Job status change and child diagnosis

Caregivers of children with epilepsy reported the highest percentage of experiencing a job status change due to caregiving (79.4%) compared to all other diagnostic groups (see table A3 in the appendix). While there was no effect of income, age and ethnicity on caregiver job status change, female and African American caregivers had a higher odds of reporting a job change compared to male (difference=2.35, 95% CI: 1.48 - 3.73, p <0.001) and white (difference=0.34, 95% CI: 0.17-0.69, p=0.003) caregivers. Caregivers of children with any diagnosis were more likely to report a job status change compared to caregivers of healthy children, except for caregivers of children with muscular dystrophy. The odds of experiencing a job status change were much higher for caregivers of children with epilepsy compared to caregivers of healthy children (OR=3.46, 95% CI: 1.94-6.19, p<0.001). Caregivers of children with Down syndrome were also more likely to report a job change compared to caregivers of healthy children (OR=1.84, 95% CI: 1.09-3.11, P <0.001), as were caregivers of children with other conditions (OR=1.74, 1.05-2.88, P=0.03) (see table 8).

### Caregiver depression and job status change

The variable stress was dropped from the model due to multicollinearity. While there was no effect of age and ethnicity on caregiver job status change, African American caregivers reported a lower mean depression score compared white caregivers (difference=3.68, 95% CI: -6.80- -0.56, p=0.02). Female caregivers reported a higher mean depression score compared to male caregivers (difference=2.01, 95% CI: 0.04 - 3.98, p=0.04). The mean depression scores were slightly lower as income increased (difference=-0.01, 95% CI: -0.01- -0.01, p=0.001). Those who experienced a job change reported a 2.95 increase in mean depression scores than those whose employment status was stable (95% CI:1.40 - 4.49, p=<0.001) (see table 9).

### Caregiver anxiety and job status change

The variable stress was dropped from the model due to multicollinearity. While there was no effect of income, age and ethnicity and race on caregiver job status change, female caregivers reported a higher mean anxiety score compared male caregivers (difference=3.30, 95% CI: 1.38-5.25, p=0.001). Those who experienced a job change reported an increase in mean anxiety scores compared to those whose employment status was stable (difference=3.61, 95% CI: 2.07-5.15, p=<0.001) (see table 10).

## Discussion

The purpose of this study was to examine the effect of various factors related to caregiver quality of life, and whether these factors vary across different child diagnoses. Table 11 summarizes the main findings of each hypothesis test. The implications of these findings are explored individually below.

### Caregiver hours

As hypothesized, caregivers of children with epilepsy reported more caregiving hours compared to caregivers of children with Down syndrome and muscular dystrophy. However, more weekly caregiving hours were not associated with greater stress. Because caregivers of children with all three diagnoses dedicated a high number of weekly caregiver hours, it is perhaps not surprising that an additional hour of caregiving per week would not lead to a significant increase in caregiver stress scores. A potential limitation of the analysis is that caregivers of healthy children and children with other conditions did not report caregiver hours as part of the survey. Comparing weekly caregiver hours against a healthy control group may provide more insight on the relationship between caregiver stress and dedicated hours.

As reported by previous research, we would expect that more dedicated caregiving hours led to greater caregiver stress (National Alliance for Caregiving, 2009a). However, this is not the case for caregivers of children with Down syndrome. While the mean caregiver hours for both children with epilepsy and Down syndrome was similar (80.4 and 77.5 hours/week respectively), caregivers of children with Down syndrome reported lower stress scores overall compared to caregivers of children with epilepsy. It is possible that caring for a child with epilepsy is more labor intensive than caring for a child with Down syndrome, which is especially true for children that experience seizures at night and therefore require additional nighttime assistance, but this study was not designed to answer this question (Al-Biltagi, 2014). Quantifying the number of caregiver hours offers information about the degree of caregiver commitment; however, future studies should investigate the types of duties the caregivers performed on a regular basis. As previously discussed, caregivers that provide assistance with basic activities of daily living are more likely to experience greater caregiver stress (Javalkar et al., 2017; Lyons et al., 2015). There may be differences in the intensity of care provided for children with epilepsy, Down syndrome and muscular dystrophy, which may account for differences in stress levels.

The mean dedicated weekly caregiver hours for caregivers of children with muscular dystrophy was the lowest (65.0) compared to the other two conditions. Severe physical limitations associated with this condition are gradual as physical function declines over several years, which may explain why weekly dedicated weekly caregiver hours were not as high compared to caregivers of children with epilepsy (Diseases - DMD - Signs & Symptoms, 2019; What Is Muscular Dystrophy?, 2019). It is also possible that families of children with muscular dystrophy utilized paid caregiver services more often compared to caregivers of children with epilepsy. However, this information was not provided in the survey. There is limited information on how often paid caregiving services are utilized for families caring for children with chronic conditions, therefore more research is needed.

### Condition severity

As hypothesized, caregivers of children with epilepsy were more likely to report caring for children with greater condition severity compared to caregivers of children with Down syndrome and muscular dystrophy. Caregivers of children with epilepsy also reported the highest mean stress scores, regardless of condition severity. This is understandable, not only because children with epilepsy are known to have more severe and different types of disabilities, but this sample included children with more severe types of epilepsy such as Dravet syndrome and other epileptic encephalopathies (Amtmann et al., 2020; Campbell et al., 2018). This may also help explain why there were no statistically significant differences in mean stress scores between caregivers of children with mild/moderate epilepsy compared to children with severe epilepsy. It is also important to note that caregivers of children with Down syndrome completed two severity questions in this questionnaire: one regarding health issues and the other regarding learning issues. The top severity score was chosen for this analysis, and the majority of the highest severity scores were due to learning issues. This may also help explain why mean stress scores for caregivers of children with Down syndrome were the lowest across all severity levels. As previously mentioned, children with Down syndrome primarily experience developmental and learning disabilities while children with muscular dystrophy largely experience greater physical limitations (*Down Syndrome*, 2012; Landfeldt et al., 2016). More research is needed to determine if caring for children with learning disabilities is associated with lower caregiver stress, especially in comparison to caring for children with medical issues. However, this analysis offers some insight into the differences in reported caregiver stress based on the different types of condition severity and disabilities associated with these three chronic conditions.

### Comorbidities

Findings from this study suggest that more of child comorbidities are not associated with greater caregiver stress for any diagnostic subgroup. This contradicts previous studies reporting increased stress with increasing number of comorbidities, which is attributed to more involved management of care (Dauphinot et al., 2016; Lee et al., 2019). However, these studies either targeted fewer comorbidities or observed comorbidities that had a higher degree of severity. In the current study, 25 different comorbidities were listed in this questionnaire, ranging from more mild conditions like allergies to more severe conditions including heart disease and rheumatic diseases. The addition of one more comorbidity did not impact stress scores of caregivers of children from any diagnostic group, which could be attributed to different types of comorbidities associated with each condition. While caregivers of children with Down syndrome reported a similar number of comorbidities compared to caregivers of children with epilepsy, their overall stress score was much lower in comparison. It is possible that children with Down syndrome had less severe comorbidities in comparison to children with epilepsy, and this may help explain why the addition of one more comorbidity did not impact stress scores for caregivers of Down syndrome. Because caregivers of children with epilepsy had a high average of total comorbidities, any additional comorbidity may be of limited impact to caregiver stress. Furthermore, while children with muscular dystrophy can have more severe physical comorbidities, because muscular dystrophy is a progressive disease, it is possible more severe comorbidities had yet to manifest in this sample. A next step for future research would be to measure the impact of specific comorbidities on caregiver stress. Due to sample size limitations for each comorbidity category, this was not possible for this analysis.

## Resilience

While higher level of resilience was associated with statistically significantly lower caregiver stress and higher caregiver benefit, the effect of resilience was consistent across all conditions. Another step in this analysis would be to examine the impact of age at onset for each condition, as caregivers that have been caring for a child with a condition for a longer period of time may have greater resilience. This has been demonstrated among caregivers caring for people with dementia, as those providing care for a longer duration reported higher resilience (Gaugler et al., 2007).

Other factors that promote resilience, such as social support and strong social connections, need to be further examined in future research. While the survey included questions about a caregiver's ability to participate in social activities, questions about social support were not included. Peer support interventions for parents of children with chronic conditions have been shown to reduce feelings of isolation, as they promote greater understanding and acceptance through shared experiences (McConnell & Savage, 2015; Nicholas & Keilty, 2007). Understanding the role of social support could provide more insight into how caregiver stress can be mitigated or managed for caregivers of children with these conditions.

In addition to individual support, understanding how different support resources are utilized for each condition would provide additional insight into how caregivers manage their child's care. Different types of respite services are offered for a range of conditions through various support organizations (including the Epilepsy Foundation, the Muscular Dystrophy Association, and the ARCH National Respite Network). However, there is limited information on how often these services are used for children with these specific conditions. Respite services are designed to provide short-term relief for primary caregivers, which can last from a couple hours to weeks (*What Is Respite Care?*, 2017). While costs of services are dependent on the type of program, most families will pay out-of-pocket as these types of services are not covered by insurance (*Respite Care: Lending a Hand to Caregivers*, n.d.) Research has shown that while caregivers who are able to utilize respite care reported reduced stress levels, the majority had issues in accessing this service, siting insufficient respite hours provided, and being placed on long waiting lists (Damiani et al., 2004; Murphy et al., 2007). Additionally, one report found that caregivers who provided 21+ hours of care and lived with their recipient were less likely to utilize paid caregiver services (National Alliance for Caregiving, 2009a). In addition to decreasing barriers to respite services, more investigation is needed to understand why some caregivers avoid utilizing these types of services.

### Job status

As hypothesized, job status change did have a significant impact on caregiver depression and anxiety. This finding reflects current literature, as caregivers that report a change in job status are more likely to report lower quality of life (*Caregiver Statistics: Work and Caregiving*, 2020; Longacre et al., 2016). Caregivers of children with epilepsy where more likely to experience a job status change in comparison to all the other diagnostic groups. An additional step in this research would be to examine not only how their job status changed, but when and for how long this change took place. Due to limitations in sample size, job status change could not be analyzed at this level of detail. Furthermore, the question regarding job status change did not include a timeframe. Caregivers that experience a more recent job status change may experience greater stress as they have yet to become acclimated to their new role.

Federal and work policies also impact caregiver decision-making when it comes to their employment status. The Family and Medical Leave Act entitles eligible employees to take "unpaid, job-protected leave for specified family and medical reasons" up to 12 weeks (*Family and Medical Leave Act*, n.d.). However, this policy does not apply to all workers, as the FMLA only covers employers with 50 or more workers (*Fact Sheet #28: The Family and Medical Leave Act*, 2012). Furthermore, not all states offer paid family leave, so fewer than 1 in 6 workers have access to paid family leave (*What States Offer Paid Family Leave for Caregivers?*, 2019). Another limitation of this policy is that it only covers up to 12 weeks of unpaid leave. While this is likely sufficient for temporary health issues, this is not adequate for long-term caregiving. While flexible work policies would provide an additional level of support, such policies are also limited or non-existent, which creates difficulties in managing work and caregiving duties (George et al., 2008). It is clear that more support for caregivers of children with chronic conditions is needed, both at a federal and community level.

### Caregiver demographics

Due to a lack of diversity in this sample, especially among the clinical diagnostic groups, conclusions based on race and gender differences may be limited. African American caregivers reported higher mean benefit scores, lower depression scores and were slightly more likely to experience a job status change compared to white caregivers. These findings are consistent with previous research, as African Americans report more a greater sense of purpose due to caregiving and lower stress compared to white caregivers (AARP & National Alliance for Caregiving, 2020). Female caregivers reported higher mean benefit scores and were more likely to experience a job status change, which is not surprising as they made up the majority of caregivers in this sample (82%). They were also more likely to report greater depression and anxiety compared to male caregivers, which reflects current literature as women are more likely to take on more caregiver duties and experience greater stress (AARP & National Alliance for Caregiving, 2020; Family Caregiver Alliance, 2019; Piran et al., 2017). Due to small sample size by race and disproportionate sampling of female and male caregivers (African Americans and male caregivers made up 6.8% and 17.6%, respectively), generalizability pertaining to racial and gender differences in the larger population may be limited until a larger study with more diverse samples is carried out.

## Limitations

While this analysis addressed different factors that negatively impact caregiving, more research is needed to understand what components are associated with positive aspects of caregiving, or caregiver benefit. In addition to the aforementioned limitations related to samples size, etc., there could also be some selection bias due to recruitment methods. Recruitment occurred through various advocacy associations, and selected caregivers may be different from caregivers who do not have access to such organizations and thus were not able to participate. It is also important to note that while caregivers were surveyed across the United States, 26% of caregivers were residents of Washington State. This could impact some differences in reported stress, as there may be different work policies, access to caregiver services, etc. On average, caregivers also reported relatively high annual incomes, which could have impacted responses as well.

## Conclusion

Caregivers of children with epilepsy reported higher levels of stress compared to caregivers of children with all other diagnoses, but this difference could not be entirely explained by this analysis. While condition severity and job status change offer some insight, limitations in this analysis prevent further assessments. Understanding the intensity of care provided, the degree of social support caregivers receive, and access to resources are important elements that need to be further explored in future research in order to fully understand differences in caregiver experience between caregivers of children with epilepsy, Down syndrome, and muscular dystrophy.

## Tables

### Table 1. Measurement tools

| Name | Domain | # of items | Response Options |
|---|---|---|---|
| UW-CSS | Stress | 19 | Likert scale: 1 (not at all), 2 (a little bit), 3 (somewhat), 4 (quite a bit), 5 (very much) |
| UW-CBS | Benefit | 13 | Likert scale: 1 (not at all), 2 (a little bit), 3 (somewhat), 4 (quite a bit), 5 (very much) |
| PROMIS Depression | Caregiver depression | 4 | Likert scale: 1 (never), 2 (rarely), 3 (sometimes), 4 |
| PROMIS Anxiety | Caregiver anxiety | 4 | Likert scale: 1 (never), 2 (rarely), 3 (sometimes), 4 (often), 5 (always) |
| UW Resilience Scale | Caregiver resilience | 6 | Likert scale: 1 (not at all), 2 (a little bit), 3 (somewhat), 4 (quite a bit), 5 (very much) |

### Table 2.a. Primary research questions: Variables that affect parental stress

| Hypothesis | Predictors | Outcome(s) | Moderator | Adjusted variables | Analysis |
|---|---|---|---|---|---|
| $H_1$ | Child diagnosis | Caregiver stress | Caregiver hours | Age, sex, race, ethnicity | Linear Regression with interaction |
| $H_2$ | Child diagnosis | Caregiver stress | Condition severity | Age, sex, race, ethnicity | Linear Regression with interaction |
| $H_3$ | Child diagnosis | Caregiver stress | Child comorbidities | Age, sex, race, ethnicity | Linear Regression with interaction |
| $H_4$ | Child diagnosis | Caregiver stress/caregiver benefit | Caregiver resiliency | Age, sex, race, ethnicity | Linear Regression with interaction |

### Table 2.b. Secondary research questions: Variables that affect potential consequences of caregiving

| Hypothesis | Predictors | Outcome(s) | Moderator | Adjusted Variables | Analysis |
|---|---|---|---|---|---|
| $H_5$ | Child diagnosis | Job status change | N/A | Income, age, sex, race, ethnicity | Logistical regression |
| $H_6$ | Caregiver stress | Depression/ Anxiety | Job status change | Income, age, sex, race, ethnicity | Linear Regression with interaction |

**Table 3. Demographic information for caregivers (n=699) and children they provide care for (n=1,364)**

| **Caregiver characteristics** | n (%) | Mean [SD] |
|---|---|---|
| Caregiver of child: | | |
| Healthy | 208 (29.7) | |
| Epilepsy | 123 (17.6) | |
| Down syndrome | 138 (19.7) | |
| Muscular dystrophy | 118 (16.9) | |
| Other health condition | 113 (16.1) | |
| Sex | | |
| Male | 123 (17.6) | |
| Female | 577 (82.4) | |
| Caregiver age | ---- | 41.5 [8.5] |
| Marital status | | |
| Married | 510 (72.9) | |
| Domestic partnership | 5 (0.7) | |
| Separated | 15 (2.1) | |
| Divorced | 15 (7.4) | |
| Living with significant other | 67 (9.6) | |
| Never married | 43 (6.1) | |
| Widowed | 8 (1.1) | |
| Education | | |
| Some high school | 22 (3.2) | |
| High school grad/GED | 100 (14.3) | |
| Some college/Technical degree/AA | 203 (29.0) | |
| College degree (BA/BS) | 216 (30.9) | |
| Advanced degree (MA, PhD, MD) | 158 (22.6) | |
| Race | | |
| While | 601 (86.5) | |
| Black | 47 (6.8) | |
| Other [a] | 47 (6.8) | |
| Ethnicity | | |
| Hispanic or Latino | 45 (6.4) | |
| Non-Hispanic or Latino | 654 (93.6) | |
| Household income | --- | $93,040 [83610]<br>Median = 72,000 |
| Employment status | | |
| Full time | 287 (41.2) | |
| Part time | 137 (19.7) | |
| Homemaker | 192 (27.6) | |
| Other | | |
| Number of children | | |
| 1 | 263 (37.8) | |
| 2 | 246 (35.3) | |
| 3+ | 187 (26.9) | |

| **Child characteristics**<br>n=1,364 | | |
|---|---|---|
| Age groups<br>0-5<br>5-10<br>6-17 | <br>425 (31.4)<br>510 (37.6)<br>420 (31.0) | |
| Sex<br>Male<br>Female | <br>736 (54.0)<br>627 (46.0) | |
| Living situation<br>live together<br>live together but child shares home with another parent/guardian<br>live separately | <br>1,258 (92.5)<br>73 (5.4)<br>28 (2.1) | |

[a] Other: Asian, Native American Indian or Alaskan Native, Native Hawaiian or other Pacific Islander, and other ethnicities

**Table 4. Mean stress scores by child diagnosis and condition severity**

| | **Condition severity**<br>**Mild/moderate** | **Severe** | **Difference in means** | **p** | **All severity levels** | **Difference between diagnosis** [a] | **Difference in means** | **p** |
|---|---|---|---|---|---|---|---|---|
| | Mean (CI) | Mean (CI) | Mean (CI) | | Mean (CI) | | | |
| **Epilepsy (EP)** | 62.5 (58.32-66.71) | 63.1 (61.61-64.55) | 0.56 (-3.76-4.88) | 0.80 | 62.34 (60.15-64.53) | DS vs EP | -8.9 | <0.001 |
| **Down syndrome (DS)** | 51.5 (49.62-53.30) | 56.5 (54.60-58.35) | 5.0 (2.38-7.66) | <0.001 | 54.06 (52.74-55.38) | MD vs EP | -5.7 | <0.001 |
| **Muscular Dystrophy (DS)** | 53.2 (51.50-54.92) | 61.2 (58.37-64.0) | 8.0 (4.77-11.18) | <0.001 | 56.46 (54.69-58.23) | MD vs DS | 3.2 | 0.003 |

[a] Difference between diagnosis for all severity levels

**Table 5. Main effects of child diagnosis, weekly caregiver hours, condition severity and their interactions on caregiver stress**

**n= 348**

| **Parameter** | **b** | **Robust SE** | **95% CI** | **p** |
|---|---|---|---|---|
| **Demographics** | | | | |
| Age | 0.04 | 0.05 | -0.06 - 0.15 | 0.45 |

| | | | | |
|---|---|---|---|---|
| Women | 2.21 | 2.12 | -1.96 - 6.39 | 0.30 |
| Non-Hispanic | -1.23 | 1.76 | -4.69 - 2.24 | 0.49 |
| Race [a] | | | | |
| African American | -0.88 | 2.42 | -5.63 - 3.88 | 0.72 |
| Other | -2.20 | 1.66 | -5.48 - 1.07 | 0.19 |
| **Main effects** | | | | |
| **Conditions [b]** | | | | |
| Down syndrome | -12.78 | 3.20 | -19.06 - 6.50 | <0.001 |
| Muscular dystrophy | -11.92 | 3.20 | -18.22 - -5.61 | <0.001 |
| **Caregiver hours** | | | | |
| Epilepsy | 0.01 | 0.02 | -0.02 - 0.05 | 0.38 |
| **Condition severity [c]** | | | | |
| Severe | 0.56 | 2.20 | -3.76 - 4.88 | 0.80 |
| **Child diagnosis*Caregiver hours interaction [b]** | | | | |
| Down syndrome | 0.02 | 0.02 | -0.03 - 0.07 | 0.35 |
| Muscular dystrophy | 0.04 | 0.03 | -0.02 - 0.09 | 0.20 |
| **Child diagnosis*Condition severity interaction [b c]** | | | | |
| Down syndrome*severe | 4.46 | 2.58 | -0.6 - 9.53 | 0.09 |
| Muscular dystrophy*severe | 7.41 | 2.71 | 2.09 - 12.74 | 0.01 |
| Constant | 59.0 | 4.21 | 50.68 - 67.25 | <0.001 |

$R^2 = 0.32$

[a] Race reference group: white caregivers

[b] Condition reference group: caregivers of children with epilepsy

[c] Severity reference group: caregivers of children with mild/moderate epilepsy

**Table 6. Main effects of child diagnosis, resilience, child comorbidities and their interactions on caregiver stress**

**n=688**

| **Parameter** | **b** | **Robust SE** | **95% CI** | **p** |
|---|---|---|---|---|
| **Demographics** | | | | |
| Age | -0.07 | 0.04 | -0.15 - 0.01 | 0.09 |
| Women | 0.14 | 0.84 | -1.52 - 1.80 | 0.87 |
| Non-Hispanic | -0.76 | 1.03 | -2.78 - 1.26 | 0.46 |
| Race [a] | | | | |
| African American | -2.02 | 1.27 | -4.52 - 0.47 | 0.11 |
| Other | 1.36 | 1.28 | -1.15 - 3.88 | 0.29 |
| **Main effects** | | | | |
| **Conditions [b]** | | | | |
| Epilepsy | 11.77 | 4.91 | 2.13 - 21.41 | 0.02 |
| Down syndrome | -5.92 | 5.74 | -17.19 - 5.35 | 0.30 |
| Muscular dystrophy | 3.91 | 5.47 | -6.84 - 14.66 | 0.48 |
| Other condition | 1.40 | 5.42 | -9.23 - 12.04 | 0.80 |
| **Resilience** | | | | |
| Healthy | -0.21 | 0.06 | -0.33 - -0.09 | 0.001 |

| | | | | |
|---|---|---|---|---|
| **Comorbidities** | | | | |
| Healthy | 0.98 | 0.53 | -0.05 - 2.01 | 0.06 |
| **Child diagnosis*Resilience interaction** [b] | | | | |
| Epilepsy | -0.04 | 0.09 | -0.22 – 0.14 | 0.65 |
| Down syndrome | 0.06 | 0.11 | -0.15 – 0.27 | 0.58 |
| Muscular dystrophy | -0.06 | 0.10 | -0.26 – 0.14 | 0.55 |
| Other condition | -0.002 | 0.10 | -0.19 – 0.19 | 0.99 |
| **Child diagnosis*Comorbidities interaction** [b] | | | | |
| Epilepsy | -0.38 | 0.57 | -1.51 - 0.75 | 0.51 |
| Down syndrome | 0.59 | 0.58 | -0.55 - 1.72 | 0.31 |
| Muscular dystrophy | -0.04 | 0.62 | -1.26 - 1.18 | 0.95 |
| Other condition | -0.16 | 0.66 | -1.45 - 1.13 | 0.81 |
| Constant | 62.86 | 3.59 | 55.81 - 69.90 | <0.001 |

$R^2 = 0.36$

[a] Race reference group: white caregivers

[b] Condition reference group: caregivers of healthy children

**Table 7. Main effects of child diagnosis and resilience and their interactions on caregiver benefit**

**n=687**

| **Parameter** | **b** | **Robust SE** | **95% CI** | **p** |
|---|---|---|---|---|
| **Demographics** | | | | |
| Age | -0.06 | 0.04 | -0.13 - 0.02 | 0.17 |
| Women | 4.40 | 0.99 | 2.46 - 6.33 | <0.001 |
| Non-Hispanic | -1.88 | 1.46 | -4.76 - 0.99 | 0.20 |
| Race [a] | | | | |
| African American | 3.63 | 1.33 | 1.03 - 6.24 | 0.01 |
| Other | -0.13 | 1.32 | -2.72 - 2.47 | 0.92 |
| **Main effects** | | | | |
| **Conditions** [b] | | | | |
| Epilepsy | 1.25 | 4.93 | -8.4 - 10.94 | 0.80 |
| Down syndrome | 4.21 | 5.87 | -7.31 - 15.73 | 0.47 |
| Muscular dystrophy | 4.59 | 5.07 | -5.36 - 14.53 | 0.37 |
| Other condition | 2.41 | 4.72 | -6.86 - 11.69 | 0.61 |
| **Resiliency** | | | | |
| Healthy | 0.31 | 0.06 | 0.20 - 0.43 | <0.001 |
| **Child diagnosis*Resilience interaction** [b] | | | | |
| Epilepsy | -0.07 | 0.10 | -0.27 - 0.13 | 0.49 |
| Down syndrome | -0.12 | 0.12 | -0.35 - 0.11 | 0.31 |
| Muscular dystrophy | -0.13 | 0.10 | -0.32 - 0.07 | 0.20 |
| Other condition | -0.01 | 0.09 | -0.20 - 0.17 | 0.89 |

| | | | | |
|---|---|---|---|---|
| Constant | 33.40 | 3.75 | 26.04 - 40.77 | <0.001 |

$R^2$ = 0.14

[a] Race reference group: white caregivers

[b] Condition reference group: caregivers of healthy children

**Table 8. Odds ratios for caregiver job status change by child diagnosis**

**n=619**

| **Parameter** | **OR** | **Robust SE** | **95% CI** | **p** |
|---|---|---|---|---|
| **Demographics** | | | | |
| Income | 0.99 | 0.01 | 0.99 - 1.00 | 0.38 |
| Age | 0.99 | 0.01 | 0.97 - 1.02 | 0.58 |
| Women | 2.35 | 0.56 | 1.48 - 3.73 | <0.001 |
| Non-Hispanic | 1.08 | 0.37 | 0.55 - 2.13 | 0.82 |
| Race [a] | | | | |
| African American | 0.34 | 0.12 | 0.17 - 0.69 | 0.003 |
| Other | 1.84 | 0.69 | 0.89 - 3.82 | 0.10 |
| Main effects | | | | |
| **Conditions** [b] | | | | |
| Epilepsy | 3.46 | 1.03 | 1.94 - 6.19 | <0.001 |
| Down syndrome | 1.84 | 0.49 | 1.09 - 3.11 | 0.02 |
| Muscular dystrophy | 1.32 | 0.35 | 0.79 - 2.22 | 0.29 |
| Other condition | 1.74 | 0.45 | 1.05 - 2.88 | 0.03 |
| Constant | 0.61 | 0.36 | 0.19 - 1.92 | 0.40 |

Pseudo $R^2$=0.08

[a] Race reference group: white caregivers

[b] Condition reference group: caregivers of healthy children

**Table 9: Main effect of job status change on caregiver depression**

**n=618**

| **Parameter** | **b** | **Robust SE** | **95% CI** | **p** |
|---|---|---|---|---|
| **Demographics** | | | | |
| Income | -0.01 | 0.01 | -0.01 - -0.01 | 0.001 |
| Age | -0.05 | 0.04 | -0.14 - 0.03 | 0.22 |
| Women | 2.01 | 1.00 | 0.04 - 3.98 | 0.04 |
| Non-Hispanic | -1.34 | 1.58 | -4.46 - 1.76 | 0.40 |
| Race [a] | | | | |
| African American | -3.68 | 1.59 | -6.80 - -0.56 | 0.02 |
| Other | -1.58 | 1.57 | -4.66 - 1.51 | 0.32 |
| **Job status change** [b] | | | | |
| Change | 2.95 | 0.79 | 1.40 - 4.49 | <0.001 |
| Constant | 54.80 | 2.45 | 49.98 - 59.62 | <0.001 |

$R^2$=0.07

[a] Race reference group: white caregivers

[b] Reference for job status change: caregivers that did not experience a job status change due to caregiving

### Table 10: Main effect of job status change on caregiver anxiety

**n=619**

| Parameter | b | Robust SE | 95% CI | p |
|---|---|---|---|---|
| **Demographics** | | | | |
| Income | -0.01 | 0.01 | -0.01 - 0.01 | 0.13 |
| Age | -0.07 | 0.04 | -0.16 - 0.01 | 0.09 |
| Women | 3.30 | 0.99 | 1.38 - 5.25 | 0.001 |
| Non-Hispanic | -1.48 | 1.44 | -4.30 - 1.34 | 0.30 |
| Race [a] | | | | |
| African American | -2.27 | 1.48 | -5.19 - 0.66 | 0.13 |
| Other | -0.99 | 1.53 | -4.0 - 2.02 | 0.52 |
| **Job status change** [b] | | | | |
| Change | 3.61 | 0.78 | 2.07 - 5.15 | <0.001 |
| Constant | 55.47 | 2.36 | 50.83 - 60.11 | <0.001 |

$R^2$=0.09

[a] Race reference group: white caregivers

[b] Reference for job status change: caregivers that did not experience a job status change due to caregiving

### Table 11. Hypotheses and summary of findings

| **Hypothesis** | **Finding** | **Conclusion** |
|---|---|---|
| $H_1$ | Caregivers of children with epilepsy reported higher caregiver hours compared to caregivers of children with Down syndrome and muscular dystrophy. However, higher caregiver hours was not associated with greater stress. | Partially supported |
| $H_2$ | Caregivers of children with epilepsy reported a higher proportion of children with a severe condition in comparison to caregivers of children with Down syndrome and muscular dystrophy. While there were statistically significant differences in mean stress scores between caregivers of children mild/moderate and severe conditions for caregivers of children with Down syndrome and muscular dystrophy, there were no statistically significant differences in mean stress scores of caregivers with mild/moderate and severe epilepsy. | Partially supported |
| $H_3$ | Mean caregiver stress scores did not increase with an increase in child comorbidities among any of the diagnostic groups. | Not supported |
| $H_4$ | The effect of resilience was not statistically significantly different among the different diagnostic groups. | Not supported |
| $H_5$ | While caregivers of children with epilepsy and Down syndrome had a higher odds of experiencing a job status change compared to caregivers of | Partially supported |

| | | |
|---|---|---|
| | healthy children, caregivers of children with muscular dystrophy did not have a higher odds of reporting a job status change. | |
| $H_6$ | Caregivers that reported a job status change were more likely to report higher levels of depression and anxiety. | Supported |

## Appendix

### Table A1: Observed means and SDs for characteristics of caregivers stratified by domain

| | **Overall** (n=699) | **Epilepsy** (n=123) | **Down syndrome** (n=137) | **Muscular dystrophy** (n=118) | **Other Condition** (n=113) | **Healthy** (n=208) |
|---|---|---|---|---|---|---|
| | Mean [SD] | Mean [SD] | Mean [SD] | Mean [SD] | Mean [SD] | Mean [SD] |
| Stress | 54.0 [9.4] | 62.9 [6.6] | 54.2 [8.0] | 53.9 [8.8] | 53.2 [8.6] | 49.1 [8.6] |
| Benefit | 47.8 [9.1] | 46.3 [8.3] | 47.3 [9.0] | 46.6 [8.8] | 50.0 [9.3] | 48.6 [9.4] |
| Depression | 53.0 [9.5] | 56.1 [8.2] | 52.2 [9.2] | 55.4 [9.2] | 54.2 [10.0] | 49.7 [9.1] |
| Anxiety | 55.1 [9.3] | 59.4 [7.7] | 54.8 [8.5] | 58.4 [9.1] | 55.5 [9.9] | 50.6 [8.6] |
| Resilience | 48.4 [9.7] | 47.4 [8.4] | 48.3 [7.4] | 47.2 [9.0] | 47.7 [11.6] | 50.2[10.9] |
| Weekly caregiver hours | 74.2 [40.7] | 80.4 [41.2] | 77.5 [39.5] | 65.0 [40.2] | ---- | ---- |
| Child comorbidities | 3.3 [2.9] | 6.0 [2.2] | 5.1 [2.4] | 3.5 [2.2] | 3.2 [2.1] | 0.36 [0.83] |

### Table A2: Child diagnosis and condition severity

| **Child Diagnosis** | **Condition severity**<br>**Mild/moderate** | **Severe** |
|---|---|---|
| Epilepsy | 16 (13.3%) | 104 (86.7%) |
| Down syndrome | 74 (53.5%) | 64 (46.4%) |
| Muscular dystrophy | 97 (82.2%) | 21 (17.8%) |

### Table A3: Child diagnosis and job status change

| | **Job status change due to caregiving** | |
|---|---|---|
| **Child Diagnosis** | **No change** | **Change** |
| Epilepsy | 22 (20.6) | 85 (79.4%) |
| Down syndrome | 42 (34.1%) | 81 (65.9%) |
| Muscular dystrophy | 46 (43.0%) | 61 (57.0%) |
| Other condition | 43 (40.2%) | 64 (59.8%) |
| Healthy | 112 (56.0%) | 88 (44.0%) |

**Table A4.a. Conditions included in the “other condition” sample**

| **Other condition** |
|---|
| Asthma |
| Autism Spectrum Disorder |
| Cancer |
| Cerebral Palsy |
| Chronic orthopedic, bone or joint problems |
| Chronic respiratory, lung or breathing trouble |
| Congenital heart disease |
| Deaf or hard of hearing |
| Diabetes High blood pressure (hypertension) |
| Inflammatory Bowel Syndrome |
| Crohn’s Disease or other intestinal disorders |
| Kidney disease |
| Legally blind |
| Rheumatic disease (JRA, rheumatoid arthritis, lupus, fibromyalgia, dermatomyositis) |
| Sickle Cell Disease |
| Speech problems |
| Thyroid disease |

**Table A4.b. Conditions included in the “Healthy” sample**

| **Healthy** [a] |
|---|
| behavioral problems |
| chronic allergies or sinus issues |
| Hyperactivity or attention deficit disorder (ADHD or ADD) |
| mental health conditions (such as depression, anxiety, bipolar disorder) |
| sleep issues (insomnia, Restless Legs Syndrome |
| behavioral problems |
| chronic allergies or sinus issues |
| Hyperactivity or attention deficit disorder (ADHD or ADD) |
| mental health conditions (such as depression, anxiety, bipolar disorder) |
| sleep issues (insomnia, Restless Legs Syndrome |

[a] Children with these conditions were not excluded from the healthy sample

## References

Aaberg, K. M., Bakken, I. J., Lossius, M. I., Lund Soraas, C., Haberg, S. E., Stoltenberg, C., Suren, P., & Chin, R. (2016). Comorbidity and Childhood Epilepsy: A Nationwide Registry Study. *PEDIATRICS*, *138*(3), e20160921–e20160921. https://doi.org/10.1542/peds.2016-0921

AARP, & National Alliance for Caregiving. (2020). *Caregiving in the U.S. 2020*. AARP. https://doi.org/10.26419/ppi.00103.001

Adib-Hajbaghery, M., & Ahmadi, B. (2019). Caregiver burden and its predictive factors in caregivers of children with chronic conditions. *International Journal of Community Based Nursing & Midwifery*, *7*(4). https://doi.org/10.30476/ijcbnm.2019.73893.0

Al-Biltagi, M. A. (2014). Childhood epilepsy and sleep. *World Journal of Clinical Pediatrics*, *3*(3), 45. https://doi.org/10.5409/wjcp.v3.i3.45

Amtmann, D., Liljenquist, K. S., Bamer, A., Gammaitoni, A. R., Aron, C. R., Galer, B. S., & Jensen, M. P. (2020). Development and validation of the University of Washington caregiver stress and benefit scales for caregivers of children with or without serious health conditions. *Quality of Life Research*, *29*(5), 1361–1371. https://doi.org/10.1007/s11136-019-02409-0

Berg, A. T., Kaiser, K., Dixon-Salazar, T., Elliot, A., McNamara, N., Meskis, M. A., Golbeck, E., Tatachar, P., Laux, L., Raia, C., Stanley, J., Luna, A., & Rozek, C. (2019). Seizure burden in severe early-life epilepsy: Perspectives from parents. *Epilepsia Open*, *4*(2), 293–301. https://doi.org/10.1002/epi4.12319

Blackwell, C. K., Elliott, A. J., Ganiban, J., Herbstman, J., Hunt, K., Forrest, C. B., Camargo, C. A., & on behalf of program collaborators for Environmental influences on Child Health

Outcomes. (2019). General Health and Life Satisfaction in Children With Chronic Illness. *Pediatrics*, *143*(6), e20182988. https://doi.org/10.1542/peds.2018-2988

Campbell, J. D., Whittington, M. D., Kim, C. H., VanderVeen, G. R., Knupp, K. G., & Gammaitoni, A. (2018). Assessing the impact of caring for a child with Dravet syndrome: Results of a caregiver survey. *Epilepsy & Behavior*, *80*, 152–156. https://doi.org/10.1016/j.yebeh.2018.01.003

*Caregiver Statistics: Work and Caregiving*. (2020, April 21). Family Caregiver Alliance National Center on Caregiving. https://www.caregiver.org/caregiver-statistics-work-and-caregiving

Chiou, H.-H., & Hsieh, L.-P. (2008). Parenting Stress in Parents of Children With Epilepsy and Asthma. *Journal of Child Neurology*, *23*(3), 301–306. https://doi.org/10.1177/0883073807308712

Cousino, M. K., & Hazen, R. A. (2013). Parenting Stress Among Caregivers of Children With Chronic Illness: A Systematic Review. *Journal of Pediatric Psychology, 38*(8), 809–828. https://doi.org/10.1093/jpepsy/jst049

*CSD*. (2019, April 17). https://www.caregiver.org/caregiver-statistics-demographics

Damiani, G., Rosenbaum, P., Swinton, M., & Russell, D. (2004). Frequency and determinants of formal respite service use among caregivers of children with cerebral palsy in Ontario. *Child: Care, Health and Development, 30*(1), 77–86. https://doi.org/10.1111/j.1365-2214.2004.00391.x

*Data and Statistics on Down Syndrome*. (2019, December 5). Data and Statistics on Down Syndrome. https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html

Dauphinot, V., Ravier, A., Novais, T., Delphin-Combe, F., Moutet, C., Xie, J., Mouchoux, C., & Krolak-Salmon, P. (2016). Relationship Between Comorbidities in Patients With Cognitive Complaint and Caregiver Burden: A Cross-Sectional Study. *Journal of the American Medical Directors Association*, *17*(3), 232–237. https://doi.org/10.1016/j.jamda.2015.10.011

*Diseases—DMD - Signs & Symptoms*. (2019, October 2). https://www.mda.org/disease/duchenne-muscular-dystrophy/signs-and-symptoms

*Down syndrome*. (2012, June). Down Syndrome - Genetics Home Reference - NIH. https://ghr.nlm.nih.gov/condition/down-syndrome

Duggleby, W., Williams, A., Ghosh, S., Moquin, H., Ploeg, J., Markle-Reid, M., & Peacock, S. (2016). Factors influencing changes in health related quality of life of caregivers of persons with multiple chronic conditions. *Health and Quality of Life Outcomes*, *14*(1), 81. https://doi.org/10.1186/s12955-016-0486-7

*Epilepsy: Meaning of Epilepsy by Lexico*. (n.d.). Epilepsy: Meaning of Epilepsy by Lexico. Retrieved April 21, 2020, from https://www.lexico.com/definition/epilepsy

*Fact Sheet #28: The Family and Medical Leave Act*. (2012). https://www.dol.gov/agencies/whd/fact-sheets/28-fmla

*Family and Medical Leave Act*. (n.d.). Family and Medical Leave Act. Retrieved April 22, 2020, from https://www.dol.gov/agencies/whd/fmla

Gaugler, J. E., Kane, R. L., & Newcomer, R. (2007). Resilience and Transitions From Dementia Caregiving. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(1), P38–P44. https://doi.org/10.1093/geronb/62.1.P38

George, A., Vickers, M. H., Wilkes, L., & Barton, B. (2008). Working and Caring for a Child with Chronic Illness: Challenges in Maintaining Employment. *Employee Responsibilities and Rights Journal*, *20*(3), 165–176. https://doi.org/10.1007/s10672-008-9065-3

Grady, P. A., & Rosenbaum, L. M. (2015). The Science of Caregiver Health: Caregiver Health. *Journal of Nursing Scholarship*, *47*(3), 197–199. https://doi.org/10.1111/jnu.12137

Hamiwka, L. D., & Wirrell, E. C. (2009). Comorbidities in Pediatric Epilepsy: Beyond ``Just'' Treating the Seizures. *Journal of Child Neurology*, *24*(6), 734–742. https://doi.org/10.1177/0883073808329527

Holmes, G. (2008, January). Types of Epilepsy Syndromes.

Hopps, M., Iadeluca, L., McDonald, M., & Makinson, G. T. (2017). The burden of family caregiving in the United States: Work productivity, health care resource utilization, and mental health among employed adults. *Journal of Multidisciplinary Healthcare*, *Volume 10*, 437–444. https://doi.org/10.2147/JMDH.S135372

Javalkar, K., Rak, E., Phillips, A., Haberman, C., Ferris, M., & Van Tilburg, M. (2017). Predictors of Caregiver Burden among Mothers of Children with Chronic Conditions. *Children*, *4*(5), 39. https://doi.org/10.3390/children4050039

Jensen, M. P., Liljenquist, K. S., Bocell, F., Gammaitoni, A. R., Aron, C. R., Galer, B. S., & Amtmann, D. (2017). Life impact of caregiving for severe childhood epilepsy: Results of expert panels and caregiver focus groups. *Epilepsy & Behavior*, *74*, 135–143. https://doi.org/10.1016/j.yebeh.2017.06.012

Joling, K. J., Windle, G., Dröes, R.-M., Meiland, F., van Hout, H. P. J., MacNeil Vroomen, J., van de Ven, P. M., Moniz-Cook, E., & Woods, B. (2016). Factors of Resilience in Informal Caregivers of People with Dementia from Integrative International Data

Analysis. *Dementia and Geriatric Cognitive Disorders*, *42*(3–4), 198–214. https://doi.org/10.1159/000449131

Kim, E.-H., & Ko, T.-S. (2016). Cognitive impairment in childhood onset epilepsy: Up-to-date information about its causes. *Korean Journal of Pediatrics*, *59*(4), 155. https://doi.org/10.3345/kjp.2016.59.4.155

Kobiske, K. R., & Bekhet, A. K. (2018). Resilience in Caregivers of Partners With Young Onset Dementia: A Concept Analysis. *Issues in Mental Health Nursing*, *39*(5), 411–419. https://doi.org/10.1080/01612840.2017.1400625

Landfeldt, E., Lindgren, P., Bell, C. F., Guglieri, M., Straub, V., Lochmüller, H., & Bushby, K. (2016). Quantifying the burden of caregiving in Duchenne muscular dystrophy. *Journal of Neurology*, *263*(5), 906–915. https://doi.org/10.1007/s00415-016-8080-9

Lee, J., Kim, S. H., Kim, Y., Kim, Y. L., & Sohn, Y. (2019). Quality of Life of Caregivers of Individuals With Parkinson’s Disease: *Rehabilitation Nursing*, *44*(6), 338–348. https://doi.org/10.1097/rnj.0000000000000158

Longacre, M. L., Valdmanis, V. G., Handorf, E. A., & Fang, C. Y. (2016). Work Impact and Emotional Stress Among Informal Caregivers for Older Adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, gbw027. https://doi.org/10.1093/geronb/gbw027

Lyons, J. G., Cauley, J. A., & Fredman, L. (2015). The Effect of Transitions in Caregiving Status and Intensity on Perceived Stress Among 992 Female Caregivers and Noncaregivers. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *70*(8), 1018–1023. https://doi.org/10.1093/gerona/glv001

Mah, J. K., Thannhauser, J. E., Kolski, H., & Dewey, D. (2008). Parental Stress and Quality of Life in Children With Neuromuscular Disease. *Pediatric Neurology*, *39*(2), 102–107. https://doi.org/10.1016/j.pediatrneurol.2008.04.011

McConnell, D., & Savage, A. (2015). Stress and Resilience Among Families Caring for Children with Intellectual Disability: Expanding the Research Agenda. *Current Developmental Disorders Reports*, *2*(2), 100–109. https://doi.org/10.1007/s40474-015-0040-z

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

*Muscular Dystrophy: Definition of Muscular Dystrophy by Lexico*. (n.d.). Retrieved April 22, 2020, from https://www.lexico.com/en/definition/muscular_dystrophy

National Alliance for Caregiving. (2009a). *2 Caregiving in the U.S. 2009*. AARP Research. https://doi.org/10.26419/res.00062.001

National Alliance for Caregiving. (2009b). *Caregivers of Children: A Focused Look at Those Caring for A Child with Special Needs Under the Age of 18*. AARP Research. https://doi.org/10.26419/res.00062.007

Nicholas, D. B., & Keilty, K. (2007). An Evaluation of Dyadic Peer Support for Caregiving Parents of Children with Chronic Lung Disease Requiring Technology Assistance. *Social Work in Health Care*, *44*(3), 245–259. https://doi.org/10.1300/J010v44n03_08

Piran, P., Khademi, Z., Tayari, N., & Mansouri, N. (2017). Caregiving burden of children with chronic diseases. *Electronic Physician*, *9*(9), 5380–5387. https://doi.org/10.19082/5380

*PROMIS–29 Profile v2.0.* (n.d.). Retrieved June 1, 2020, from http://www.healthmeasures.net/administrator/components/com_instruments/uploads/15-09-02_02-16-11_PROMIS-29Profilev2.0InvestigatorVersion.pdf

*Respite Care: Lending a Hand to Caregivers*. (n.d.). Respite Care: Lending a Hand to Caregivers. Retrieved April 21, 2020, from https://www.epilepsy.com/article/2014/3/respite-care-lending-hand-caregivers

Rosa, F., Bagnasco, A., Aleo, G., Kendall, S., & Sasso, L. (2017). Resilience as a concept for understanding family caregiving of adults with Chronic Obstructive Pulmonary Disease (COPD): An integrative review. *Nursing Open*, *4*(2), 61–75. https://doi.org/10.1002/nop2.63

*StataCorp. 2013.* (Version Stata Statistical Software: Release 13). (2013). [Computer software].

Stoneman, Z. (2007). Examining the Down syndrome advantage: Mothers and fathers of young children with disabilities. *Journal of Intellectual Disability Research*, *51*(12), 1006–1017. https://doi.org/10.1111/j.1365-2788.2007.01012.x

*University of Washington Caregiver Benefit Scale (UW-CBS) Version 1 Users Guide*. (2017). https://uwcorr.washington.edu/measures/uw-cbs-userguide.pdf

*University of Washington Caregiver Stress Scale (UW-CSS) Version 1 Users Guide*. (2017). https://uwcorr.washington.edu/measures/uw-css-userguide.pdf

*University of Washington Resilience Scale (UWRS) Version 1 Users Guide*. (2017). https://uwcorr.washington.edu/measures/uw-resil-userguide.pdf

Valderas, J. M., Starfield, B., Sibbald, B., Salisbury, C., & Roland, M. (2009). Defining Comorbidity: Implications for Understanding Health and Health Services. *The Annals of Family Medicine*, *7*(4), 357–363. https://doi.org/10.1370/afm.983

*What are the types of muscular dystrophy?* (2016, December 1). https://www.nichd.nih.gov/health/topics/musculardys/conditioninfo/types

*What conditions or disorders are commonly associated with Down syndrome?* (2017, January 31). What Conditions or Disorders Are Commonly Associated with Down Syndrome? https://www.nichd.nih.gov/health/topics/down/conditioninfo/associated

*What is Muscular Dystrophy?* (2019, December 2). https://www.cdc.gov/ncbddd/musculardystrophy/facts.html

*What Is Respite Care?* (2017, May 1). What Is Respite Care? Retrieved from https://www.nia.nih.gov/health/what-respite-care

*What States Offer Paid Family Leave for Caregivers?* (2019, November 19). https://www.aarp.org/caregiving/financial-legal/info-2019/paid-family-leave-laws.html

Zhao, X. (2016). Resilience in the Context of Informal Caregiving: A Scoping Study. *Medical Research Archives*, *4*(6). https://doi.org/10.18103/mra.v4i6.690