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Do characteristics of children and families influence reported caregiver burden? : a secondary data analysis of the 2009-2010 national survey of children with special health care needs

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DO CHARACTERISTICS OF CHILDREN AND FAMILIES INFLUENCE REPORTED CAREGIVER BURDEN? A SECONDARY DATA ANALYSIS OF THE 2009-2010 NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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Families Influence Reported
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Abstract

Children with special health care needs (CSHCN) make up 15% of U.S. children 18 and under. They require increased specialized care, which may pose unique challenges to families. Prior research suggests families from historically disenfranchised groups may experience greater burden due to systems of structural oppression. This quantitative secondary data analysis of the 2009-2010 National Survey of CSHCN (N=40,242) uses a cross-sectional design, testing whether family characteristics (race/ethnicity, caregiver's gender or education level, and number of CSHCN in the home) or a child's functional difficulty (chronic pain, behavior, anxiety/depression) are significantly associated with caregiver burden. Results suggest significantly greater time, financial, and employment burden is placed on female caregivers of CSHCN and that functional difficulties are significantly associated with caregiver burden. Findings suggest opportunities for additional legislative reform and investments in clinical work to mitigate the disproportionate burden placed upon CSHCN from historically disenfranchised communities.

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CHAPTER I

Introduction

In the United States, an estimated 11,203,616 children or 15.1% of all children ages 0-17 have a special health care need.[1] These children exist within family systems that need to provide specialized care to meet the complex and varied needs of this population. Children with special health care needs, or CSHCN, are defined as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (Child and Adolescent Health Measurement Initiative, 2012, p. 1). Nothing fully prepares parents and caregivers for what life will be like raising any child, however it is common for caregivers of CSHCN to confront unique challenges and additional stressors associated with these varied needs, especially among more-complex CSHCN (Kuo, Cohen, Agrawal, Berry, & Casey, 2011). Specifically, caregivers in these families are at risk of various problems in relationship to their child's chronic health issues, including financial and employment hardships depending on the presence and severity of various child factors and household characteristics (Looman, O'Conner-Von, Ferski, & Hildenbrand, 2009).

CSHCN carry a wide range of mental, behavioral, and health conditions and, and as defined here, all require more specialized care and services than would be expected for children

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[1] A national survey of 371,617 households in 2009-2010 revealed 59,941 children who had special health care needs (National Survey of Children with Special Health Care Needs).

their age without special health care needs. While providing specialized care is likely stressful in all families, the burden across families can be disproportionate (Musumeci, 2017). Drawing on literature based in intersectionality, systems theory, and social ecological perspectives, this thesis examines the disproportionate risk and vulnerability for caregiver burden that may exist for families that embody specific sociocultural identities, as well as how characteristics of the individual, the family system, and their sociocultural location are associated with disproportionate caregiver burden. This area of interest matters to the field of social work because better understanding the burden experienced by families of the CSHCN population can aid social workers in responding to these concerns more empathically and effectively, and because research involving historically disenfranchised populations may increase access to needed services and advance social justice in the realm of health care.

To begin, specific sociocultural identifies, including gender, race/ethnicity, and family income are associated with higher prevalence of children with special health care needs (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2013). Caregiving burden in having CSHCN exists due to the epidemiological profile for CSHCN as well as the structural systems in place that disadvantage some social groups. For example, 17.4% percent of all boys are estimated to be CSHCN, while 12.7% of all girls are. By race/ethnicity, 17.5% of Black children, compared to 16.3% of White children, and 11.2% of Hispanic children are estimated to be CSHCN. (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2013). Accordingly, these families may also experience a greater extent of associated physical, emotional, and economic burden. To best asses the dynamic experiences in this population, it is important to test the effect of and to understand the intersectionality of these identities and to acknowledge the increased risk for burden that families with specific sociocultural traditions, psychosocial identities and structural challenges may experience.

The identified research questions of this study address these assessment priorities within the CSHCN population. First, this study examines specific functional difficulties that CSHCN may have such as chronic pain, behavior issues, and anxiety/depression. Second, this study examines the characteristics of families of CSHCN such as race/ethnicity, caregiver gender, caregiver education level, and the number of CSHCN in the home. Third, this study examines whether any functional difficulties or family characteristics are significantly associated with caregiver burden. Caregiver burden is broken down into specific measures of the effect on a caregiver's time, finances, and employment. Lastly, this study examines the individual contributions of the unique family characteristics and functional difficulties to estimates of reported caregiver time, financial, and employment burden.

Ultimately, it may be possible to create specific interventions that target populations most at risk for experiencing burden and to be proactive about creating opportunities for early intervention. This is especially pertinent because existing research has found that with increased medical diagnoses and care needs, families experienced increased rates of unmet needs (Kuo et al., 2011). As previously stated, all CSHCN experience an increased need for specialized services, which is associated with high levels of family burden. Examining this burden, how it manifests, and how it can be decreased is therefore vital to continuously improve the variety of care and to help facilitate more positive outcomes for affected children and families. Existing social service programs may be models of interventions that already respond to this burden that families experience. For example, Supplemental Security Income (SSI) provides financial support to people with disabilities who have limited income and resources. Qualifying families of children with disabilities may benefit from this assistance and therefore experience less financial burden than families who do not receive SSI. Questions such as this one drive this work to quantitatively measure the prevalence of various types of burden that families of CSHCN are experiencing, to identify characteristics of families and children associated with burden, and to consider implications for new programs that respond to the disproportionate burden of vulnerable subpopulations of CSHCN and their families.

CHAPTER II

Literature Review

This literature review first outlines the key dependent variables of interest (caregiver time, financial, and employment burden) and highlights how these terms have been operationalized in existing literature. Next, there is a review of the prevalence of these dependent variables as well as an examination of the documented effects that each of them has had on caregivers and families of CSHCN. This literature review then identifies this study's covariates (race/ethnicity, gender, number of CSHCN, education level, and specific functional difficulties) and details the rationale for their inclusion and their significance to research within the CSHCN population. The chapter goes on to identify factors related to CSHCN, caregivers, families, and larger systems and to discuss documented theories that explain the proposed relationship between these factors and caregiver burden. Special attention is paid to an acknowledgement of the role of sociocultural location in experiences of burden and intertwined marginalization through the lens of intersectionality. Next, there is an examination within existing literature of the role of stress and its potential as a contributing mechanism to caregiver burden. Lastly, gaps in the existing literature and ways that this study fills these gaps are explored.

Definitions of Burden

It is a widely-accepted viewpoint in existing literature that caring for a child with special health care needs (CSHCN) presents unique challenges for the involved family. These challenges have been operationalized in various ways depending on the goal of the research. Multiple definitions exist, in the literature, placing emphasis to varying degrees on how CSHCN may require greater resources from the caregiver, family, and society, at large. Researchers have broadly defined burden as “an overall term in order to describe the physical, emotional, and economic consequence of providing care” (Carretero, Garcés, Ródenas, & Sanjosé, 2009, p. 75). Yet others focus more directly on the physical, psychological, and emotional toll (rather than the economic consequences) that providing care for CSHCN requires of caregivers. In this paper “caregiver burden” is defined as the physical, emotional, and economic consequence of providing care to a CSHCN. As described below, the extant literature on caregiver burden operationalizes the physical, emotional, and economic consequences through examinations of the burden on a caregiver’s time, finances, and employment.

Caregiver time burden. Some ways that time burden may be operationalized, specifically from the National Survey of Children with Special Health Care Needs (NS-CSHCN) are the amount of time spent providing direct health care for the CSHCN in the home, the amount of time spent coordinating health care between multiple providers for the CSHCN in the home, or the combination of the previous two (Miller et al., 2015). Ghandour, Hirai, Blumberg, Strickland and Kogan (2014) identified that spending greater than 10 hours per week on care provision and coordination to be an indicator of burden.

Caregiver financial burden. Financial burden has been measured in both absolute and relative terms. When measured in absolute terms, financial burden is the amount of money spent in the last twelve months on health care costs. Relative terms are operationalized as the amount of money spent in the last twelve months as a proportion of a family’s total income (Parish, Rose, Dababnah, Yoo & Cassiman, 2012). While some research defined financial burden as gross spending, financial burden has also been understood as a subjective measure of a family’s self-reported perceived financial troubles regardless of income or spending (Ghandour et al., 2014).

Caregiver employment burden. Employment burden encompasses challenges such as caregivers changing their job, quitting work completely, or reducing the number of hours that they work as a direct result of tending to the care of their CSHCN and to living amidst the consequences of the child's condition. Some definitions have also included a consideration of the degree to which a caregiver may remain employed at a job that provides them little personal satisfaction but perhaps has financial or insurance benefits that help with supporting caretaking efforts for the CSHCN (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2013)

Prevalence and Effect of Burden among Caregivers and Families with CSHCN

Having established the various ways that caregiver burden has been defined and operationalized in existing literature on this topic, researchers have then reported statistics and findings related to the prevalence of these types of burden, the other variables related to the burden, and the effect that these types of burden have had on individuals and families. The current study focusses on caregiver burden of a time, financial, and employment nature and as such, below is a review of pertinent literature that also covered these three domains.

Time burden. Families that care for CSHCN have been found to spend a lot of time providing this care, and therefore may experience family time burden. Research has shown that various individual, familial, and societal factors play a role in families experiencing or not experiencing time burden. For example, Miller et al. (2015) found that among CSHCN that were in the sample from the 2009-2010 NS-CSHCN, the following were associated with higher time burdens: non-White race, more severe or unstable health condition in the child, the family having public health insurance, the family lacking a medical home, and caregivers having low income and low adult education. A statistical analysis reported in the 2009-2010 NS-CSHCN chartbook said that caregivers of 39.2% of CSHCN spent under one hour per week arranging and coordinating care, that 37.2% spent between one and four hours per week, and lastly that 13.1% spent eleven or more hours on these tasks (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2013).

Financial burden. In analyzing data from the 2000-2002 NS-CSHCN, Kuhlthau, Hill, Yucel, and Perrin (2005) found that 40% of families with CSHCN experienced burden of a financial nature that was related to their child's medical condition. This trend has been found to be relevant across multiple years as well, as comparison studies between 2001 and 2009-2010 have shown that over this period there have been increases in financial burden for families of CSHCN (Ghandour et al., 2014). As in any research, prevalence is dependent on how each variable is defined. Statistics from the 2009-2010 NS-CSHCN chartbook reported that 21.6% of all CSHCN lived in families that experienced financial problems due to caring for the CSHCN. Furthermore, 23.1% of CSHCN who came from families with lower incomes had conditions that led to financial problems, compared to 14.9% of CSHCN from higher income families (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2013).

Employment burden. In a secondary data analysis of the 2005-2006 NS-CSHCN, Kuo et al. (2011) found that a staggering 54.1% of the sample reported that a family member ceased working due to the child's health. On a more promising note, it appears that there is some evidence of improvement over the last decade, as Ghandour et al. (2014) reported a decrease of employment burden for families of CSHCN between 2001 and the 2009-2010 period. This study identified the following possible covariates: child's sex, child's age, race and ethnicity, household poverty, urban vs. rural residence, severity of the child's condition, and the status/type of insurance held by the family.

By 2009-2010, the subgroup of CSHCN that were insured, regardless of publicly or privately, were less likely to reside in families experiencing employment burden. No change was noted in employment burden over time for the caregivers of the most severely functionally limited CSHCN, however, those with milder limitations were more than 40% less likely to have caregivers impacted by employment burden in 2009-2010 relative to 2001 (Ghandour et al., 2014). This shows that the presence and severity of caregiver employment burden can be mediated by the family's insurance coverage and by the severity of the child's condition. Regarding employment decisions as they may relate to concerns for maintaining health insurance that covers a CSHCN, it has been found that 17.7% of the 2009-2010 NS-CSHCN respondents self reported that they avoided job changes for this reason (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2013).

Effects of caregiver burden. It is vital to identify the factors that are associated with caregiver burden because increased burden among this population is associated with a variety of negative individual and familial outcomes. More research needs to be done and more efforts made to decrease burden and ameliorate the detriments of living with chronic burden. For example, when studying a term defined as "psychiatric morbidity" among family caregivers, Yee and Shulz (2000) reported that overall, caregivers experienced depression, anxiety, and high stress. The same study also showed that these negative effects were more likely to be developed by female caregivers than their male counterparts. Additionally, increased levels of caregiving responsibility, higher numbers of hours spent caregiving, and more severe deterioration of the care recipient were associated with an increased risk of experiencing the above listed negative outcomes.

Another reason why it is vital to define and to describe the risk factors of excessive caregiver burden is because when caregivers experience burden, one consequence can be acting out in aggressive and violent ways towards the people that they care for in acts of both maltreatment and abuse (Mockus Parks & Novielli, 2000). Other research has discovered a negative association between caregiver burden and utilization of preventative dental care amongst CSHCN—an association found in both CSHCN with and without functional limitations (Chi, McManus, & Carle, 2014). This provides preliminary evidence that families with greater burden are more likely to experience more serious health care needs in the future due to an underutilization of preventative services, which could be costly for families and for the health care system at large. Carretero et al. (2009) reported that living with the care recipient was associated with increased depression, increased social isolation and decreased caregiver health. Overall, there is evidence of caregiver burden having negative effects on future outcomes and wellbeing.

Rationale for Covariates

The current study tests the association between measures of independent variables (race/ethnicity, gender, number of CSHCN, caregiver education level, child's chronic physical pain, child's behavior problems, child's anxiety/depression) and different types of caregiver and family burden (time, financial, employment) within the CSHCN population.

Race/ethnicity. In line with research by Miller, Nugent, and Russell (2015), it is hypothesized that in this sample, caregivers of color will be more likely to experience increased levels of financial, employment, and time burden compared to their White counterparts. A caregiver’s race exists within systems of structural violence and racism, which throughout history have led to limited opportunities for occupational growth and for ending cycles of poverty. As a result, it has become more burdensome for caregivers of color to adequately provide for their CSHCN. These disparities in accessing easy-to-use, and therefore less burdensome services, were studied by Rosen-Reynoso, Porche, Kwan, Bethell, Thomas, Robertson, Hawes, Foley, and Palfrey (2016). This research found that the lack of access to health services for CSHCN fell most prominently on children from racial minority backgrounds and those that live in poverty.

Racial and class-based disparities are “rooted in inequities in social and environmental determinants of health (e.g. poverty, income inequality, maldistribution of educational and other resources, racism, and environmental injustice) and the failure of public policies to address them” (Council on Community Pediatrics and Committee on Native American Child Health, 2010, p. 839) Miller et al. (2015) used data from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to examine time burden (not financial or employment) as influenced by independent variables such as family income, age, and race, considering them to be factors predisposing to burden. This study found that non-White race was associated with higher time burdens. The same study showed that being a low-income caregiver was linked to increased time burden, therefore it is hypothesized that people with the intersectional identity of low-income caregivers of color may experience the highest levels of time burden. Because the amount of time that one needs to spend providing care may likely also be linked to one’s job and finances, it is further hypothesized in this study that the same is true for both financial and employment burden.

Gender. Gender is another covariate examined in the current study in considering the potential relationship to various forms of caregiving burden associated with CSHCN. In a study comparing caregiver burden in families raising children with disabilities and caregiver burden in families raising typically developing children, researchers found that mothers had higher levels of burden than fathers (Roper et al., 2014). To parse out whether increased burden and negative outcomes for female caregivers compared to male counterparts could be attributed to the act of caregiving itself, Yee and Schulz (2000) examined gender differences in psychiatric symptoms (i.e. depression, anxiety, high stress level) of family caregivers. These authors found both that female caregivers reported more of these symptoms than male caregivers, and that when compared to a sample of people who were not caregivers, excess psychiatric symptoms reported by female caregivers could be explained by caregiving. For these reasons, gender is an important covariate to study and it is hypothesized that female caregivers will report experiencing more time, financial, and employment burden than male caregivers.

Number of CSHCN. Regarding the number of CSHCN in the home as a covariate, it is hypothesized that caregivers of multiple CSHCN will experience more caregiver burden than those with a single CSHCN in the home. As such, it is thought that additional CSHCN in a family unit will generate additional family and caregiver burden because caring for any child has been linked to stress and because stress has a crucial role in parenting (Crnic, Gaze, & Hoffman, 2005). Additionally, research on how family planning decisions are made may also clarify the roles of stress and burden for caregivers. For example, a study by Frost and Lindberg (2013) found women reported that wanting to preserve a sense of control in their life was one of the most common reasons for engaging in active forms of family planning. This research suggests that use of contraception or measures to control the timing of pregnancy may be efforts to reduce stress and caregiver burden, and suggests that there may be a link between caregiver burden and the number of children that a family is caring for.

Education. In this study, education level is another covariate thought to impact caregiver burden. It is hypothesized that a caregiver's level of education will be positively correlated with that caregiver's income, and therefore that education level will be a significant factor in moderating the prevalence and type of burden experienced by caregivers of CSHCN. Lindley and Mark (2010) found that families with lower socioeconomic status perceived more financial burden at lower levels of expenditures than families of higher socioeconomic status. This provided evidence that socioeconomic status may be a familial factor that affects the amount and type of burden that families of CSHCN experience. It has also been shown that low caregiver education can be a predisposing factor associated with higher time burden, meaning that low education was associated with elevated chances of experiencing high time burden (Miller et al., 2015).

Specific types of functional difficulties. In this study, three specific types of functional difficulties that CSHCN may experience were chosen as independent variables: chronic physical pain, behavior problems, and anxiety/depression. Research has shown that these three specific domains of health and functional status were the most valuable for adults to pay attention to. Specifically, adults wanted to avoid having their children experience these health conditions for their children, perhaps because these conditions would elicit the highest levels of caregiver burden or parenting difficulties (Craig, Brown, & Reeve, 2015). As suggested by that research, it is important to consistently determine where the priorities of the public lie, which promotes "buy in" in improving national child health. The current study examines these difficulties as covariates to better understand the other family and child characteristics and predisposing factors related to chronic physical pain, behavior problems, and anxiety/depression to supplement this research.

Theory of Factors Associated with Family Burden

Taken completely and applying social work-based lenses of social ecological perspectives and systems theory, it may also be understood that burden is a product of factors at multiple levels of human experience and within multiple family or interpersonal dynamics. McDonald, Poertner and Pierpont (1999) described an ecological perspective as emphasizing "the interrelatedness of person in environment, an interaction that is seen as a dynamic, goal-oriented process" (p. 101). Additionally, they described systems theory as a framework in which "each component of a system is dependent on all others and [in which] intricate relationships between components are developed to achieve a dynamic equilibrium or homeostasis" (p. 101). Breaking this theory down reveals a micro level in which there are predisposing and characterological factors related to the specific individuals providing and receiving care. Through this lens, CSHCN are both individuals and parts of caregiving-care receiving dyads, which affect the overall functioning of a family system.

Drawing on this framework, each family is also affected by the organizations with which they interact, including but not limited to Early Intervention Services (EI), health care settings, and schools. These organizations and the CSHCN-caregiver dyads are also positioned within an even larger context of broad community and geographic locations. On a macro-level, therefore, the systems become even more complex with consideration of factors related to society, and overarching political and economic constraints.

Figure 1 below provides a schematic overview of how various factors may interact including the characteristics of the child and their caregivers, as well as those of the family and the service delivery systems within which they interface.

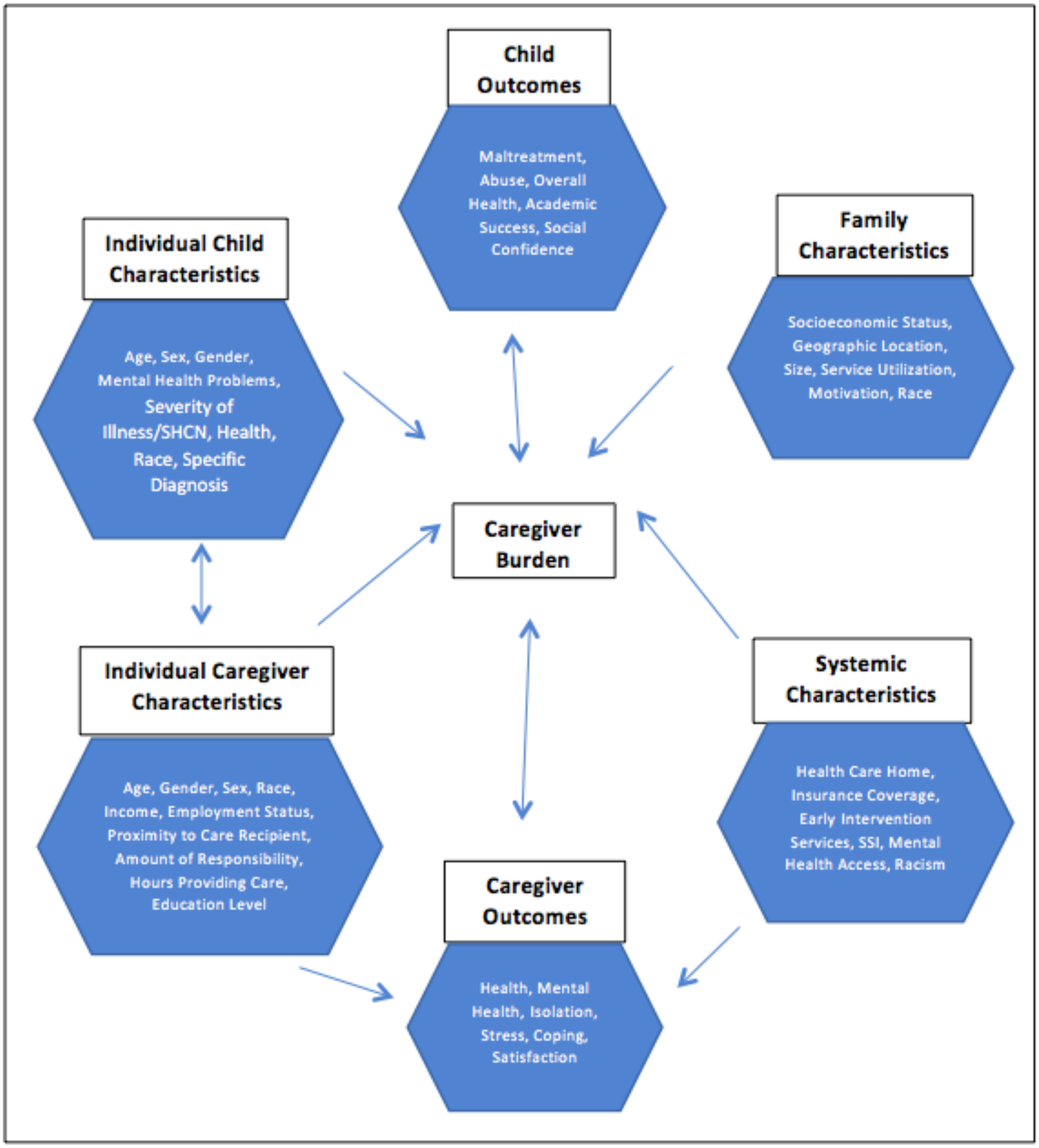

Figure 1. *Factors related to caregiver burden. This figure illustrates hypothesized factors and directionality on measures of caregiver burden.*

Individual child characteristic factors. Within the current literature, characteristics of CSHCN have been found to be related to caregiver burden. Some of these characteristics include age, gender, mental health and health conditions, severity of illness, race, and the specific diagnosis. These factors embody research looking at the sociocultural locations of people who are dependent on caregivers and searching for patterns related to caregiver burden. For example, a care recipient's young age and male gender have been found to be associated with increased general caregiver burden (Gaugler, Kane, & Langlois, 2000). Furthermore, individuals who have behavioral problems that are the result of a variety of mental disorders are found to have caregivers that also experience excessive levels of burden (Carretero et al., 2009. The degree of illness severity that the care recipient has can also play a role in increased caregiver burden, specifically related to employment (Mears, 1998). In the 2000-2002 NS-CSHCN data collected from Minnesota, more severe conditions were associated with parents reporting increased levels of financial and employment problems (Looman et al., 2009).

In the 2009-2010 NS-CSHCN, poorer child health was associated with increased probability of the family experiencing time burden (Miller et al. 2015). Another study showed that younger CSHCN (aged 0-5 years) have been found to be more likely to live in families with employment burden, while their older counterparts (aged 12-17 years) were more likely to live in families with financial burden (Ghandour et al., 2014). This suggests that individual factors, like the age of the care recipient, can influence the type of burden that a family may experience. Race has also been shown to be an individual predisposing factor for various types of familial burden. For example, being a person of color was related to higher time burden (Miller et al., 2015).

Specific child diagnoses have also been shown to be associated with having various impacts on families. For example, Vohra, Madhavan, Sambamoorthi and St. Peter (2014) found that children with Autism Spectrum Disorder (ASD) from the 2009-2010 NS-CSHCN were more likely to have families with financial burden, employment burden, and time burden than children with developmental disabilities or other mental health conditions. A study by Dabrowska and Pisula (2010) examined levels of parenting stress among biological parents of children ages 2-6 who were typically developing, who had autism, and who had Down-Syndrome. While this specific sample was not drawn from a NS-CSHCN, it found that parents of children with autism indicated higher levels of stress, and that mothers of these children reported more parental stress than fathers—a gendered effect that was not found among parents in the other study groups. Together this research lends itself to an understanding that a child's characteristics are likely to impact the severity, and in some cases the type, of burden that their caregivers may experience, and as such, specific functional difficulties of the CSHCN are included as potential covariates in this study.

Individual caregiver and family characteristic factors. Other existing research examined a group of factors one step removed from the primary care recipient. These factors are related to characteristics of the dependent individual's caregiver, family dynamic, or proximal environment. In this vein, a study on informal caregiving by Navaie-Waliser, Spriggs and Feldman (2002) found that caregivers were more likely to experience high levels of burden if they were young, female, low income, and employed. Similarly, low socioeconomic status, low education, and living in a rural setting were all predisposing factors that made caregivers more likely to experience elevated time burden in Miller et al.'s (2015) research. Carretero et al. (2009) posited that living with the person to whom one is providing care, as would likely be true in a parent-child dyad, was associated with high levels of excessive burden. The same was shown by Looman et al. (2009) to be associated with parent report of financial and employment problems among families of CSHCN. Additionally, and especially among families where children had more severe conditions that family members were providing the care for in-home, parents reported both financial and employment issues that they identified as stemming from the child's condition (Looman et al., 2009). In sum, because of these findings, the current study includes race/ethnicity, caregiver gender, number of CSHCN, and caregiver education level as covariates

Systemic characteristic factors. One systemic factor that has been examined quite heavily in the literature on caregiver and family burden is the presence and establishment of a Health Care Home. A pediatric health care/medical home is defined as "a model of care that promotes holistic care of children and their families, provides management of both acute and chronic issues, and provides an ongoing relationship with a health care professional for each family" (Drummond, Loopman & Phillips, 2012, p. 267). In a study on coping among parents of CSHCN, families that had a health care home reported to be better able to cope and were more satisfied with provider communication (Drummond et al., 2012). While this study did not look at family or caregiver burden as a dependent variable, the increased ability to cope and the enhanced provider communication suggest the potential to alleviate caregiver burden. In a subsequent study, Miller et al. (2015) reported that CSHCN who did not have a medical home had higher odds of living in a family experiencing time burden than those who did have a medical home, suggesting that health care homes may buffer some aspects of family and caregiver burden. Similarly, Ghandour, Perry, Kogan and Strickland (2011) explored the medical home's mediating role in the relationship between mental health symptoms and family burden in the CSHCN population. Using data from the 2005-2006 NS-CSHCN, this study concluded that the care coordination aspects of the medical home model at least slightly mediated the relationship between emotional/behavioral symptoms in children and the family's financial and employment-related burden.

Another systemic factor is insurance, which has been shown in existing literature to be an indicator of the prevalence of family burden. Ghandour et al. (2014) found that CSHCN with private insurance were less likely than their publicly insured or uninsured counterparts to be in families that reported employment and general forms of caregiver burden. Having public health insurance has been associated with higher chances of time burden, both in parents spending time providing care and in parents spending time arranging and coordinating care among health care providers (Miller et al., 2015). Income inequality, on a geographic and state-based level, has also been found to be associated in various ways to family burden. For example, a secondary data analysis of the 2005-2006 NS-CSHCN found that families of CSHCN who resided in states that overall have higher rates of income inequality, self-report increased amounts of financial burden (Parish et al., 2012). Overall, this research shows that the larger context within which families exist may determine the probability of the family with CSHCN experiencing burden related to their situation.

Intersectionality. While it is important to consider the previously stated factors and their individual impact on family burden, intersectionality is a concept that offers a way to consider the interaction between various factors and examine the combinatory effect on burden. In its founding sense, the term "intersectionality" was coined by Kimberlé Crenshaw to refer to the idea that "multiple marginalizations, such as those experienced by African-American women, are mutually constituted and could not be understood or ameliorated by approaches that treated race and sex/gender as distinct subjects of inquiry" (Bauer, 2014, p. 11). As such, this concept was originally employed to look specifically at the intersection of race and gender, however in more recent research, intersectionality has been expanded and found to be applicable to other social categories that may also be interconnected.

In an article by Else-Quest and Hyde (2016), the authors laid out the following three positions that intersectionality assumes: that humans are defined by more than one distinction and that these distinctions are interrelated, that there should be an acknowledgement of the roles of inequality and power as they relate to these distinctions, and lastly that these distinctions are relevant both to the individual and to the social context within which the individual exists. Intersectionality is applicable to the current study because of the importance of its role in researching health equity in diverse populations. Specifically, “intersectionality has the potential to enrich population health research through improved validity and greater attention to both heterogeneity of effects and causal processes producing health inequalities” (Bauer, 2014, p. 10).

A Disparities Framework: Examining Relationship between Sociocultural Location and Caregiver Burden

Disparities in health care between racial and ethnic groups have been defined in multiple ways. For the purposes of this study, disparity will be defined as suggested by Cook, McGuire and Zaslavsky (2012): “disparities are differences in health care services received by the two groups [non-Latino Whites and racial/ethnic minority groups] that are not due to differences in the underlying health care needs or preferences of members of the groups” (p. 1235). Per this definition, disparity encompasses the legal/regulatory climate of the health care system, as well as discrimination rooted in stereotypes and biases. Existing literature examined disparities in access to health care services among the CSHCN population asking what factors were related to higher ease in obtaining needed services. Results have shown that while approximately 33.3% of families with CSHCN encounter some difficulty in accessing health care services, lack of access was most prevalent for children with the most complex medical, emotional, or behavioral needs and for those from racial/ethnic minority backgrounds or poor families (Rosen-Reynoso et al., 2016).

Mechanisms Contributing to Burden of Caring for CSHCN: The Role of Stress

There is likely no singular experience of caring for a CSHCN, however research has identified a dynamic and compounding influence that the stress associated with burden can present. In relation to overburdened caregivers for children with major mental illnesses, Lefley (1989) described them as "suffering from the pain of [their] child's illness, the stigmatization of having 'caused' it, and the burden of overseeing a treatment plan that may be unrealistic in terms of time, energy, money, and demands from the rest of the family" (p. 558). Burden is also often seen as interchangeable, if not closely related, with stress. In a study that compared caregiver burden in families of children with disabilities and families of typically developing children, it was noted that stresses within families were rooted in various realms including family problems, child behavioral and social issues, and lack of resources or support (Roper, Alfred, Mandleco, Freeborn & Dyches, 2014).

One way to conceptualize how these stressors infiltrate a family and result in such burden is by using Transactional Stress Theory (Lazarus & Folkman, 1984). In this theory, stress is defined as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 21). This theory also acknowledges the role that the environment plays on an individual's ability to cope with the consequences of their environment, as well as the well-being of an individual as an eventual outcome of being impacted by excessive stress. In the current study, burden is understood as specific physical, emotional, and economic consequences of providing care to a CSHCN.

Caregiver and family burden emerges, therefore, as a function of multi-directional, transactional stress between the child, the surrounding family, and society when a threshold of tolerance has been surpassed. Depending on the most salient factors for these entities, the burden manifests in time, financial, or employment-related ways. An example is that for families with CSHCN, the elevated need for health and related services, as compared to the general pediatric population, presents potentially unique strains on both the resources and relationships of family members. Per Transactional Stress Theory, family members are influenced by their environment to create an appraisal of the child's condition, which causes them to react and provide care in a specific way, which eventually leads to short-term and longer-term outcomes that can be desired or undesired. Based on this model, influencing factors may include caregiver characteristics or systemic characteristics, both of which can greatly impact long term outcomes such as overall social functioning and familial well-being. Because of this, research that identifies what these influencing factors are and how they may interact with one another through intersectionality theory is crucial to pursue.

Another mechanism that serves to understand the role of stress is the Stress Process Model, originally by Pearlin, Mullan, Semple, and Skaff (1990). The model suggests that stress manifests itself based on variables related to the caregiving context, and that these variables also affect the type of stress that caregivers experience, how caregivers perceive these stressors, and the long-term outcome of the caregiver including both physical and mental health indicators (Hilgeman, Durkin, Sun, DeCoster, Allen, Gallagher-Thompson & Burgio, 2009). Specific variables that the Stress Process Model includes are a caregiver's age, gender, employment status, and relationship to the care recipient. Notably this model does not include race as a variable. Compared to Transactional Stress Theory, which suggests that caregivers appraise their situation based on their environment, the Stress Process Model focuses more on caregivers appraising their situation based on their own characteristics or subjectivity.

Hilgeman et al. (2009) used the Stress Process Model as a backbone for a study that tested race as a moderator of the relationship between resources and “intrapsychic strain” in their sample of caregivers of people with Alzheimer’s disease. Intrapsychic strain was defined as the “infringement of the caregiving role into the CG’s [caregiver’s] ability to maintain a sense of personal identity” (Hilgeman et al., 2009, p. 252). This was measured though the following variables: confidence in caregiving, caregiving skills, and rewards associated with caregiving. Conceptually, intrapsychic strain is caregiver stress that can be very specifically identified as being rooted in the caregiver’s perception of loss of self because of providing care. This study found that a caregiver’s race moderated the impact of resources on intrapsychic strain, meaning that when the level of resources available were higher, White caregivers experienced higher levels of intrapsychic strain than caregivers of color.

In the Stress Process Model, the caregiving context interacts with objective stressors, role strains, intrapsychic strain, outcome, subjective stressors, and resources. Overall. this model supports the notion that individual, familial, and societal factors are associated with family burden. For example, a caregiver’s role may be strained by having a child with particularly severe health care needs and may also have psychic strain due to racism and to having limited confidence in their ability to provide adequate care, and thus may experience high levels of burden and end up with negative outcomes. The way that factors interact and compound one another is particularly interesting and warranting of further analysis.

Gaps in Current Literature

As mentioned previously, current literature documents the multiple child, family, and systems level factors that are associated with caregiver and family burden experienced by families of CSHCN. Per a theoretical and empirical review by Carretero et al. (2009), prior studies examine variables related to the dependence of a care recipient on their caretaker at length as well as the disease that the dependent person has, while less research exists that examines how influential the characteristics of the care recipient can be on caregiver burden. What needs to be studied further is how the child and family characteristics are specifically associated with caregiver time, financial, and employment burden to more precisely identify ways to decrease the strain within this population. What also merits further research are the individual effects of the unique child and family characteristics when adjusted for other factors. Within this frame, there is limited literature on incorporating intersectionality theory into population health research even though "greater application of intersectionality within population health research has the potential to improve researcher's collective ability to more specifically document inequalities within intersectional groups, and to study the potential individual- and group-level causes" (Bauer, 2014, p. 15). This study lays the groundwork for intersectional research initiatives through identifying the prevalence of proposed covariates in the CSHCN population.

Overall, the current study will execute a secondary data analysis of the 2009-2010 NS-CSHCN to fill these gaps in the literature. Research findings hold important implications at the macro level to provide evidence to inform federal and state policy and on a micro level to help social workers and clinicians better understand the unique needs of this CSHCN population, and therefore to more effectively assess and treat their needs in sensitive and informed ways.

CHAPTER III

Methodology

The following chapter describes the purpose of this quantitative study's research questions and rationale as well as the subjects, data source, and analytic approach.

Formulation - Research Purpose and Design

This study investigates the types of burden that caregivers of children with special health care needs (CSHCN) across the United States experience, as well as the factors and sociocultural characteristics that may influence the type and severity of this burden. This study accomplishes this goal through a quantitative secondary data analysis of the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). As such, hypotheses are proposed pertaining to factors that might influence the extent of burden that families of CSHCN experience. The study employs a cross-sectional study design with bivariate and multivariate statistical tests to understand the role of sociocultural location on three types of burden that caregivers of CSHCN experience.

The study employs an incremental approach to statistical analyses, beginning with descriptive statistics and subsequently employing bivariate and multivariate analyses. After descriptive and bivariate analyses, the study employs a logistic regression to be able to consider the effect of race, gender, number of CSHCN in the home, and specific type of SHCN (e.g. chronic physical pain, behavioral problems, anxiety/depression) when controlling for other factors influential to family burden. This study design allows testing of hypotheses about the impact of sociocultural factors on burden of illness while controlling for other factors hypothesized to be influential to caregiver burden. The Smith College School for Social Work Human Subjects Review Committee reviewed the proposed study and granted exemption from committee review due to the use of a de-identified secondary dataset, the 2009 – 2010 National Survey of Children with Special Health Care Needs (see appendix A). This research is important because the results may help identify how social disadvantage influences three different types of caregiver burden. The results may also help to identify key correlations that would ideally help inform and improve social welfare and health care policy and would also help educate medical or mental health providers to better meet the needs of the children and families that they provide care to and interact with daily.

Research Questions and Rationale

The following is a list of research questions that were developed to lay the foundation for better understanding the complexity of the needs of families with CSHCN. Given that the original survey was fielded to facilitate national analyses, questions were also crafted keeping in mind a desire to perhaps uncover ways to improve the various systems that CSHCN and their caregivers need to be involved with. As such, these questions emerged from theories of factors related to family burden drawing from ecological perspectives and systems theory, as described in more detail by McDonald et al. (1999). Drawing on these theoretical frameworks and prior empirical work outlined in the introduction and literature review, it is hypothesized that caregiving for CSHCN may place disproportionate burden on caregivers from socially disadvantaged communities. Research questions first capture the extent of financial, employment, and time burden among all families and then propose additional sub-analyses to characterize the differences in burden among certain sub-populations. The research questions posed in this study specifically include:

1. What percentage of U.S. parents/guardians providing care to CSHCN report experiencing time burden in 2009-2010?
    - A. What is the association between specific types of functional difficulties (ex. chronic physical pain, behavior problems, anxiety/depression) and reported time burden?
    - B. What is the association between proposed covariates (gender of primary caregiver, race/ethnicity, number of CSHCN, level of education) and time burden?
2. When looking at a model of covariates (gender of primary caregiver, race/ethnicity, number of CSHCN, level of education, type of functional difficulty), which variables significantly contribute to estimates of reported time burden?
3. What percentage of U.S. parents/guardians providing care to CSHCN report experiencing financial burden in 2009-2010?
    - A. What is the association between specific types of functional difficulties (ex. chronic physical pain, behavior problems, anxiety/depression) and reported financial burden?
    - B. What is the association between proposed covariates (gender of primary caregiver, race/ethnicity, number of CSHCN, level of education) and financial burden?

4. When looking at a model of covariates (gender of primary caregiver, race/ethnicity, number of CSHCN, level of education, type of functional difficulty), which variables significantly contribute to estimates of reported financial burden?
5. What percentage of U.S. parents/guardians providing care to CSHCN report experiencing employment burden in 2009-2010?
    A. What is the association between specific types of functional difficulties (chronic physical pain, behavior problems, anxiety/depression.) and reported employment burden?
    B. What is the association between proposed covariates (gender of primary caregiver, race/ethnicity, number of CSHCN, level of education) and employment burden?
6. When looking at a model of covariates (gender of primary caregiver, race/ethnicity, number of CSHCN, level of education, type of functional difficulty), which variables significantly contribute to estimates of reported employment burden?

Further research is needed about the association between the type of a child's special health care need and the burden placed upon the family. This study first proposes to conduct bivariate analyses of the key independent variables (types of functional difficulties of CSHCN), covariates, and each of the three dependent variables of interest. Bivariate analyses will inform the variables included in the multi-variate models examining predictors of time, financial, and employment burden.

Subjects and Sample

The primary sampling frame for the 2009-2010 NS-CSHCN was defined as U.S. households with a child between 0 and 17 years old living in the home. This sample was selected as it was already available from a previous Center for Disease Control and Prevention (CDC) National Immunization Survey. The Maternal and Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (Child and Adolescent Health Measurement Initiative, 2012, p. 1). To identify these children and include them in this research, eligibility was determined using the CSHCN screener. This screener was developed by the Child and Adolescent Health Measurement Initiative of the Foundation of Accountability.

The screener’s intention is to focus on chronic health and the associated consequences (van Dyck, McPherson, Strickland, Nesseler, Blumberg, Cynamon, & Newacheck, 2002). 372,698 children were screened using this instrument, which asks base questions about general health, and then follow up questions assessing chronic nature and severity of the reported health conditions. Children were considered CSHCN if they had affirmative responses to a minimum of one base question and the subsequent follow up questions (Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002). Responses were provided by a child’s parent or guardian who understood the health of the resident children. Inclusion criteria require that the child in the home must be 0-17 years old, with no inclusion or exclusion criteria related to other demographic characteristics such as gender or race. According to the Center for Disease Control and Prevention (2011), 40,242 CSHCN interviews were completed. For each question asked in the survey, participants had the option to select an answer of “don’t know” or “refuse to answer.” Those responses were excluded from analysis and as such, some of the 40,242 interviews were excluded, as can be seen in total N amounts in Table 4. Per Ghandour et al. (2014), who also analyzed the 2009-2010 NS-CSHCN, the interview completion rate was 80.8%. The nationally representative sampling framework is one of the strengths of this survey. As such, findings of this research may be more validly generalized to other children and families who did not take part in the original survey and can be used (with appropriate weights) to make national estimates.

Data Source

The data source for the current study is the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). This survey is a telephone-based tool for data collection that aims to gather information on specific demographics, needs, and family dynamics of children living with specialized health care needs. Vohra et al. (2014), who also analyzed the 2009-2019 NS-CSHCN, described the data source as "representative of the US civilian noninstitutionalized population with children ages 0-17 years" (p. 817). The NS-CSHCN exists within the context of a goal to develop more efficient and higher quality care for these children, and as such, hopes to provide both the federal Maternal and Child Health Bureau (MCHB) and the federal and state level Children with Special Health Care Needs programs with systematic data capturing the prevalence and impact of these needs among this population (van Dyck et al., 2002). The survey was initially established to provide "estimates of the number of children with special health care needs in each state and to characterize their health and functional status, the types of services that they need and use, and shortcomings in the system of care" (van Dyck et al., 2002 p. 30). With repetition over time, the survey may uncover data that measure and illuminate progress in improving the systems of care that most impact families of CSHCN.

For the purposes of the current study, data was pulled from the 2009-2010 survey, which is the most recent data available. It was primarily funded by the United States Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA) and MCHB (Center for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, 2011). The data analyzed was made public by these corporations as a free and de-identified data set. The specific SPSS indicator data set for the current study was prepared by the Data Resource Center for Child and Adolescent Health (2009/10 National Survey of Children with Special Health Care Needs). Once families made it past the screening phase, those identified as having a resident CSHCN went on to answer a full host of questionnaire items that covered ten domains identified as being significant for policy and epidemiology: demographics, health and functional status, health insurance coverage, adequacy of health insurance coverage, public program participation, access to health care, health care utilization, care coordination, satisfaction with services, and impact on family (van Dyck et al., 2002). The survey includes open-ended, multiple choice, Likert scale, and dichotomous polar questions. The analyses reported for the current study are about the set of CSHCN who were identified through the screener (N = 40, 242).

For the 2009-2010 NS-CSHCN data collection took place between July 7, 2009 and March 2, 2011 (Center for Disease Control and Prevention, 2011). Once gathered, final data were organized into three separate yet linkable files: Screener (all age-eligible children), Household (all households regardless of CSHCN), and CSHCN Interview (all CSHCN). There are some noteworthy limitations of this data set including the fact that data from 1,081 children were omitted to protect confidentiality. Also, because the survey was household based, it does not capture the diverse experiences of any children living in institutions such as schools, hospitals, or residential treatment facilities. Despite the limitations, strengths of using this data for a secondary data analysis include a large, national, and representative sample that lends itself to generalizability of the current study's results. Furthermore, the results of this research may help to identify key factors and multiple variables that affect family burden in the United States among families providing care for CSHCN, and in turn help give suggestions for improving the lives of these people.

Based on the measures that are significant for the current study Appendix B lays out an examination of existing literature and shows how prior studies have operationalized these measures in a variety of ways. Below, Table 1 provides a list of the key dependent and independent variables with descriptions of their respective definitions. A codebook is provided that describes the various domains of importance covered in this research, along with the ways in which the response sets are described in the CSHCN interview survey (Appendix C).

Table 1

Operational Definitions of Key Dependent and Independent Variables

<table>
<tr><th colspan="3">Key Dependent Variables</th></tr>
<tr><th>Measure</th><th>Operational definition</th><th>References to prior studies</th></tr>
<tr><td>Time Burden</td><td>Survey respondent reports that family spends 11 or more hours/week providing and/or coordinating/arranging care for CSHCN.</td><td>Ghandour et al., (2014)
Miller et al., (2015)</td></tr>
<tr><td>Financial Burden</td><td>Survey respondent reports that conditions of CSHCN cause financial problems for the family.</td><td>Ghandour et al., (2014)
Kuhlthau et al., (2005)</td></tr>
<tr><td>Employment Burden</td><td>Survey respondent or another family member has stopped working because of child's health or survey respondent or other family members has cut down on # of work hours because of child's health conditions or survey respondent or another family member has avoided changing jobs due to concern for maintaining health insurance for child.</td><td>Ghandour et al., (2014)
Looman et al., (2009)
Vohra et al., (2014)</td></tr>
<tr><th colspan="3">Key Independent Variables</th></tr>
<tr><th>Measure</th><th>Operational definition</th><th>References to prior studies</th></tr>
<tr><td>Race/ Ethnicity</td><td>Race and ethnicity of children in CSHCN population: Hispanic, White (non-Hispanic), Black (non-Hispanic), Asian (non-Hispanic), Other (non-Hispanic).</td><td>Ghandour et al., (2014)
Hilgeman et al., (2009)
Miller et al., (2015)</td></tr>
</table>

Gender	Gender of survey respondent caring for CSHCN: Male, Female.	Navaie-Waliser et al., (2002) Yee & Schulz, (2000)
Number of CSHCN	Number of CSHCN reported to be in the home: one, more than one.	Vohra et al., (2014)
Education Level	Highest level of school that any parent in the household has completed or the highest degree any parent in the household has received: less than high school, high school graduate, more than high school education.	Miller et al., (2015) Vohra et al., (2014)
Chronic Physical Pain	Child's level of difficulty with repeated physical pain including headaches: none, a little, a lot.	Craig et al., (2015)
Behavior Problems	Child's level of difficulty with behavior problems including acting out, fighting, arguing, and bullying: none, a little, a lot.	Carretero et al., (2009) Craig et al., (2015) Ghandour et al., (2011) Rosen-Reynoso et al., (2016)
Anxiety/Depression	Child's level of difficulty with feeling anxious or depressed compared to other children their age: none, a little, a lot.	Craig et al., (2015) Vohra et al., (2014)

Data Analysis and Analytic Plan

The 2009-2010 NS-CSHCN is a de-identified, publicly available data set, which for this research was obtained through a data use agreement with the Data Resource Center and their Child and Adolescent Health Measurement Initiative (CAHMI). The objective of CAHMI is to facilitate dissemination and utilization of the results of the National Health Surveys. Some data from the original sample was excluded before this release to the public to protect the confidentiality of participants (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2013). This is one noted limitation of using this data set for the current study.

Data sets were first downloaded and converted from SAS format to .csv format and linked together using unique child identification numbers titled IDNUMXR. In this excel format, the analytic plan first involved assessment of potential measures listed previously in Table 1 by examining frequency tables and descriptive statistics for each central variable, paying specific attention to frequencies of any missing data. Based on quality of variables and conceptual importance of them, variables were selected, with development of new variables to address data quality concerns or ensure alignment with the proposed theoretical perspective. The selected variables for this analysis were operationalized based on both existing literature and novel approaches that built upon previous research (see Appendix B). Data was coded based on the codebook of original and developed measures (see appendix C); variables arrive from the Questionnaire (in English) available from the CDC (see Appendix D) and was processed with the assistance of Marjorie Postal, Smith School for Social Work. Unknown or missing values were participant responses to questions coded as “don’t know” or “refuse to answer” and were not included in the denominator when determining prevalence estimates. According to the Data Resource Center, for the chosen variables the proportion of unknown values is under 1% and therefore excluding the unknown and missing data from the analysis does not change the prevalence estimates or percentages (National Survey of Children with Special Health Care Needs, 2009/10). This choice was conceptual in nature, as there is no way to accurately predict whether a response of “don’t know” or “refuse” is the same as a “no.”

Statistically significant correlations between independent and dependent variables were tested with chi-square statistics, with an adopted level of significance at p = .000. This significance level was chosen per the recommendations of data analyst Marjorie Postal, and likely accommodates the large sample size of this study and acknowledges the potential for spurious associations at level of p = .05. For example, chi-square tests were run between caregiver gender and burden (financial, employment, time), between caregiver race and burden (financial, employment, time), between child presence of mental health/behavioral challenges and their caregiver’s burden (financial, employment, time), and between the number of CSHCN in the home and caregiver burden (financial, employment, time). Bivariate analyses were conducted to examine relationships between key independent and dependent variables without controlling for any potential modifiers.

Multivariate analyses were conducted that considered the possible role that key variables have in impacting the relationship between independent variables and dependent outcomes. For example, examining the most common type of burden for people who care for children with mental health/behavioral challenges after controlling for race, gender, and the caregiver's education level. Regression models were created that incorporated factors related to burden. The rationale for this methodology is that logistic regressions allow for estimation of effect for a binary outcome adjusting for potential covariates. A linear regression could not be used because having a binary outcome variable does not meet assumptions of linearity.

Despite this study's significant efforts to advance the current literature there are a few noted limitations of this analytic plan. First, the cross-sectional study design does not allow for conclusions of causal relationships between the independent and dependent variables that were analyzed. Second, the outcome measures were operationalized in one way, which while purposefully chosen, are only one possibility of many and therefore results may have varied should other ways of defining the variables been used. As part of the analytic plan, variable construction/cleaning and frequency tests were run for each covariate, key independent variable, and key dependent variable. Appendix E shows the original response set, the recode that was done, and the new current study variable. Once recoded, frequencies were run.

Research Questions and Bivariate Analyses

After the initial frequencies of key independent and dependent variables were run, bivariate analyses were run to analyze differences among groups as well as key relationships. For example, as outlined below in Table 2, a chi-square statistical test was the bivariate analysis used to determine the relationship between time burden and caregiver gender. Chi-square tests were used to test the number of people surveyed who fell within the specific categories of relevance. Table 2 also outlines the other relationships that were examined along with the associated research questions and hypotheses.

Table 2

Bivariate Analysis of Key Relationships

Research Question	**Hypothesis**	**Dependent Variable**	**Independent Variable**	**Statistical Test**
Is there a difference in time burden by gender of primary caregiver?	Female caregivers will report more time burden than male caregivers.	Time Burden (TBD) - Binary	Caregiver Gender (CG) - Binary	Chi-Square Test
Is there a difference in time burden by race /ethnicity?	Caregivers from minority races/ethnicities will report more time burden than White caregivers.	Time Burden (TBD) - Binary	Race/Ethnicity (RE) - Categorical	Chi-Square Test
Is there a difference in time burden by the number of CSHCN in the home?	Caregivers with >1 CSHCN will report more time burden than caregivers with 1 CSHCN.	Time Burden (TBD) - Binary	Family Size (FS) - Binary	Chi-Square Test
Is there a difference in time burden by education level?	Caregivers with lower levels of education will report more time burden than those with higher levels of education.	Time Burden (TBD) - Binary	Household Parent's Education Level (PEL) - Ordinal	Chi-Square Test
Is there a difference in financial burden by gender of primary caregiver?	Female caregivers will report more financial burden than male caregivers.	Financial Burden (FBD) - Binary	Caregiver Gender (CG) - Binary	Chi-Square test
Is there a difference in financial burden by race /ethnicity?	Caregivers from minority races/ethnicities will report more financial burden than White caregivers.	Financial Burden (FBD) - Binary	Race/Ethnicity (RE) - Categorical	Chi-Square test
Is there a difference in financial burden by the number of CSHCN in the home?	Caregivers with >1 CSHCN will report more financial burden than	Financial Burden (FBD) - Binary	Family Size (FS) - Binary	Chi-Square Test

	caregivers with 1 CSHCN.			
Is there a difference in financial burden by education level?	Caregivers with lower levels of education will report more financial burden than those with higher levels of education.	Financial Burden (FBD) - Binary	Household Parent's Education Level (PEL) - Ordinal	Chi-Square Test
Is there a difference in employment burden by gender of primary caregiver?	Female caregivers will report more employment burden than male caregivers.	Employment Burden (EBD) - Binary	Caregiver Gender (CG) - Binary	Chi-Square Test
Is there a difference in employment burden by race /ethnicity?	Caregivers from minority races/ethnicities will report more employment burden than White caregivers.	Employment Burden (EBD) - Binary	Race/Ethnicity (RE) - Categorical	Chi-Square Test
Is there a difference in employment burden by the number of CSHCN in the home?	Caregivers with >1 CSHCN will report more employment burden than caregivers with 1 CSHCN.	Employment Burden (EBD) - Binary	Family Size (FS) - Binary	Chi-Square Test
Is there a difference in employment burden by education level?	Caregivers with lower levels of education will report more employment burden than those with higher levels of education.	Employment Burden (EBD) - Binary	Household Parent's Education Level (PEL) - Ordinal	Chi Square Test
What is the association between chronic physical pain and reported time burden?	There will be a positive correlation between chronic pain and time burden (the higher the chronic pain the higher the time burden).	Child's Chronic Physical Pain Level (CPL) – ordinal	Time Burden (TBD) - Binary	Chi-Square Test
What is the association between behavior problems and reported time burden?	There will be a positive correlation between behavior problems and time burden (the higher the behavior problems the higher the time burden).	Child's Behavior Problems (BPL) - ordinal	Time Burden (TBD) - Binary	Chi-Square Test
What is the association between anxiety/depression and reported time burden?	There will be a positive correlation between anxiety/depression and reported time burden (the higher the	Child's Anxiety/Depression Level (ADL) - ordinal	Time Burden (TBD) - Binary	Chi-Square Test

	anxiety/depression the higher the time burden).			
What is the association between chronic physical pain and reported financial burden?	There will be a positive correlation between chronic pain and financial burden (the higher the chronic pain the higher the financial burden).	Child's Chronic Physical Pain Level (CPL) - Ordinal	Financial Burden (FBD) - Binary	Chi-Square Test
What is the association between behavior problems and reported financial burden?	There will be a positive correlation between behavior problems and financial burden (the higher the behavior problems the higher the financial burden),	Child's Behavior Problems (BPL) - Ordinal	Financial Burden (FBD) - Binary	Chi-Square Test
What is the association between anxiety/depression and reported financial burden?	There will be a positive correlation between anxiety/depression and reported financial burden (the higher the anxiety/depression the higher the financial burden).	Child's Anxiety/Depression Level (ADL) - Ordinal	Financial Burden (FBD) - Binary	Chi-Square Test
What is the association between chronic physical pain and reported employment burden?	There will be a positive correlation between chronic pain and employment burden (the higher the chronic pain the higher the employment burden).	Child's Chronic Physical Pain Level (CPL) - Ordinal	Employment Burden (EBD) - Binary	Chi-Square Test
What is the association between behavior problems and reported employment burden?	There will be a positive correlation between behavior problems and employment burden (the higher the behavior problems the higher the employment burden).	Child's Behavior Problems (BPL) - Ordinal	Employment Burden (EBD) - Binary	Chi-Square Test
What is the association between anxiety/depression and reported employment burden?	There will be a positive correlation between anxiety/depression and reported employment burden (the higher the anxiety/depression the higher the employment burden).	Child's Anxiety/Depression Level (ADL) - ordinal	Employment Burden (EBD) - Binary	Chi-Square Test

Research Questions and Multivariate Model Analyses

Following the bivariate analyses, a multivariate logistic regression was run to determine the extent to which each independent variable of interest influenced the key dependent variables for the current study. The models were run incrementally, adding type of SHCN after modeling sociodemographic variables of the family. Results presented in the next chapter include characteristics of the child as inclusion generated a final model that provided improved explanatory value of the model. Measurements of race/ethnicity in this statistical test, only one dummy race variable (White/not White) was used because of low percentages in the other categories (Hispanic 11%, Black 10%, Other 9%). Table 3 below outlines the regression model that was run.

Table 3

Multivariate Analysis of Key Relationships

Outcome	**Predictive Variables**	**Method**
Financial Burden (FBD) - Binary	-Caregiver Gender (CG) -Race/Ethnicity (RE) -Household Parent's Education Level (PEL) -Family Size (FS)	Logistic regression
Employment Burden (EBD) – Binary	-Caregiver Gender (CG) -Race/Ethnicity (RE) -Household Parent's Education Level (PEL) -Family Size (FS)	Logistic regression
Time Burden (TBD) – Binary	-Caregiver Gender (CG) -Race/Ethnicity (RE) -Household Parent's Education Level (PEL) -Family Size (FS)	Logistic regression
Financial Burden (FBD) - Binary	-Caregiver Gender (CG) -Race/Ethnicity (RE) -Household Parent's Education Level (PEL) -Family Size (FS) -Child's Chronic Physical Pain Level (CPL) - with dummy variables as indicators for each level of scale. -Child's Behavior Problems Level (BPL) - with dummy variables as indicators for each level of scale.	Logistic regression

	-Child's Anxiety/Depression Level (ADL) - with dummy variables as indicators for each level of scale.	
Employment Burden (EBD) – Binary	-Caregiver Gender (CG) -Race/Ethnicity (RE) -Household Parent's Education Level (PEL) -Family Size (FS) -Child's Chronic Physical Pain Level (CPL) - with dummy variables as indicators for each level of scale. -Child's Behavior Problems Level (BPL) - with dummy variables as indicators for each level of scale. -Child's Anxiety/Depression Level (ADL) - with dummy variables as indicators for each level of scale.	Logistic regression
Time Burden (TBD) – Binary	-Caregiver Gender (CG) -Race/Ethnicity (RE) -Household Parent's Education Level (PEL) -Family Size (FS) -Child's Chronic Physical Pain Level (CPL) - with dummy variables as indicators for each level of scale. -Child's Behavior Problems Level (BPL) - with dummy variables as indicators for each level of scale. -Child's Anxiety/Depression Level (ADL) - with dummy variables as indicators for each level of scale.	Logistic regression

CHAPTER IV

Findings

This study assessed characteristics of CSHCN and their families on caregiver-reported experiences of time, financial, and employment burden through the 2009-2010 NS-CSHCN. The findings that follow below start with frequencies of caregiver demographics (gender, race/ethnicity, number of CSHCN in the home, and education level), and CSHCN demographics (chronic physical pain, behavioral problems, anxiety/depression). Next, prevalence, bivariate and multivariate models are provided in turn for each of the key dependent variables of interest for this analysis, specifically caregiver report of time, financial, and employment burden.

Descriptive Statistics – Child and Family Characteristics of the Sample

Respondents for this sample of 40,242 completed CSHCN interviews included 75% mothers (biological, step, foster, or adoptive), 17% fathers (biological, step, foster, or adoptive), 6% grandparents, and 2% other types of guardians. Of note, 69.6% of the sample self-identified as White, while a combined 30.5% as people of color. Most of the families surveyed (80%) had one CSHCN, while the remaining 20% had more than one. Regarding education level, 79.7% of the caregivers in the sample achieved education beyond high school, while 14.9% stopped after high school and 5.3% before finishing high school. Many children had high levels of difficulty associated with their special health care needs, with 6% reporting high chronic physical pain, 13.3% high behavioral issues, and 13.1% of the sample reporting high anxiety/depression.

Table 4

Frequencies of Independent and Dependent Variables

Frequencies	*N*	*% of total*
Independent Variables		
Gender		
Female	30,059	75
Male	6,942	17.3
Race/Ethnicity		
Hispanic	4,479	11.1
White, non-Hispanic	27,989	69.6
Black, non-Hispanic	4,010	10.0
Other, non-Hispanic	3,764	9.4
Number of CSHCN in the Home		
1 CSHCN	32,180	80
2+ CSHCN	8,062	20
Household Parent's Education Level		
Less than High School	2,145	5.3
High School Graduate	6,007	14.9
More than High School	32,090	79.7
Child's Chronic Pain Level		
High	2,432	6.0
Low	8,470	21.0
None	29,213	72.6
Child's Behavioral Problem Level		
High	5,360	13.3
Low	9,558	23.8
None	24,365	60.5
Child's Anxiety/Depression Level		
High	5,269	13.1
Low	11,239	27.9
None	22,672	56.3
Dependent Variables		
Time Burden		
Yes	4,984	12.4
No	34,384	85.4
Financial Burden		
Yes	8,087	20.1
No	31,847	79.1
Employment Burden		
Yes	12,808	31.8
No	27,183	67.5

Time Burden: Prevalence and Factors Influential to Time Burden

Prevalence of time burden (unadjusted). In this sample, 12.4% of the caregivers (n=4,984) of CSHCN reported experiencing time burden because of coordinating and providing care.

Bivariate associations. Bivariate analyses examined the association between the specific types of functional difficulties of CSHCN and time burden. For CSHCN, 13.3% of caregivers of children with chronic pain, 27.8% of children with behavioral problems, and 26.5% of children with anxiety/depression reported time burden. Significant association was found between the child's chronic pain level and time burden (Chi square (2, n=39,249) =771.57, p=.000), child's behavior problem level and time burden (Chi square (2, n=38,430) =1733.21, p=.000), and child's anxiety/depression level and time burden (Chi square (2, n=38,334) =1002.42, p=.000).

Table 5 below also shows the association between other independent variables hypothesized to be associated with caregiver time burden. Nearly four of every five female caregivers surveyed (83.7%) reported experiencing time burden while under one in five males (16.3%) reported experiencing time burden. The association between gender and time burden was significant (Chi square (1, n=36,379) =21.097, p=.000). Also, 58.4% of White caregivers surveyed reported experiencing time burden compared to 16.1% of the Hispanic caregivers, 14.4% of the Black caregivers and 11% of the other category. The association between race and time burden was significant (Chi square (3, n=39,368) =388.34, p=.000). Of note, for measurements of race/ethnicity in multivariate analyses, only one dummy race variable (White/not White) was used because of low percentages in the other categories (Hispanic 11%, Black 10%, and Other 9%).

Of those caregivers who reported experiencing time burden, approximately three quarters (77.6%) had one CSHCN while just under a quarter (22.4%) had two or more CSHCNs. As hypothesized the association between number of CSHCN in the home and time burden was significant (Chi square (3, n=39386) =388.34, p=.000). While 66.6% of CSHCN caregivers with education beyond high school surveyed reported experiencing time burden, 23.1% of those with a high school education and 10.4% of those with below a high school education reported experiencing time burden. As hypothesized, the association between education level and time burden was significant (Chi square (2, n=39,368) =715.37, p=.000). A greater percentage of caregivers with higher levels of education compared to their counterparts with lower levels of education reported experiencing time burden.

Table 5

Relationship Between Key Independent Variables and Time Burden (TBD)

Factors	**Caregivers of CSHCN not experiencing TBD** (N = 34,384) *%*	**Caregivers of CSHCN experiencing TBD** (N = 4,984) *%*
Gender*** cc		
Female	80.8	83.7
Male	19.2	16.3
Race/Ethnicity***		
Hispanic	10.2	16.1
White, non-Hispanic	71.6	58.4
Black, non-Hispanic	9.1	14.4
Other, non-Hispanic	9.1	11.0
Number of CSHCN in the Home***		
1 CSHCN	80.4	77.6
2+ CSHCN	19.6	22.4
Household Parent's Education Level***		
Less than High School	4.4	10.4
High School Graduate	13.3	23.1
More than High School	82.2	66.6
Child's Chronic Pain Level***		
High	5.0	13.3
Low	20.0	28.0
None	75.0	58.7
Child's Behavioral Problem Level***		
High	11.5	27.8
Low	23.8	28.1
None	64.7	44.1
Child's Anxiety/Depression Level***		
High	11.6	26.5
Low	28.1	32.9
None	60.3	40.5

Note: TBD, time burden; *** Significant difference in p = .000

"cc" denotes use of continuity correction; other differences were tested using Pearson Chi-Square tests.

Multivariate model of time burden. A logistic regression test was run to allow for consideration of the relative effect of key independent variables (caregiver gender, race/ethnicity, caregiver education level, number of CSHCN, child's chronic pain level, child's behavioral problems, and child's anxiety/depression) when adjusted for potential covariates (female caregiver, non-White race, greater than one CSHCN, low/high chronic pain, low/high behavior problems, low/high anxiety/depression). The overall model was significant (Chi square=1625.33, p=.000) with a Nagelkerke r square of .09. Table 6 below shows the results.

First, caregiver gender was statistically significant (p=.000). Female caregivers were 1.046 times more likely than males to report time burden, when adjusted for other covariates. This result was consistent with hypotheses that female caregivers would report greater time burden than male counterparts.

Second, race/ethnicity was also statistically significant (p=.000). Caregivers of color were .623 as likely to report time burden, when adjusted for other covariates. This finding was contrary to the hypothesis expecting that supposed greater time burden would be reported among caregivers of color as compared to White caregivers.

Third, number of CSHCN in the home was also statistically significant (p=.01). Caregivers caring for more than one CSHCN were 1.11 times more likely than those with only one CSHCN in the home to report time burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers with more CSHCN would report greater time burden than counterparts with only one CSHCN.

Fourth, caregiver education level was also significant (p=.000), when adjusted for other covariates. Increased education level was found to increase the odds of experiencing time burden.

Fifth, child's chronic pain level was also statistically significant (p=.000). Caregivers of CSHCN with any chronic pain were 1.708 times more likely than caregivers whose CSHCN had no chronic pain to report time burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with chronic pain would report greater time burden than those caring for CSHCN without chronic pain.

Sixth, child's behavior problem level was also statistically significant (p=.000). Caregivers of CSHCN with any behavior problems were 1.579 times more likely than caregivers whose CSHCN had no behavioral problems to report time burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with behavioral problems would report greater time burden than those caring for CSHCN without behavioral problems.

Lastly, child's anxiety/depression level was also statistically significant (p=.000). Caregivers of CSHCN with any anxiety/depression were 1.586 times more likely than caregivers hose CSHCN had no anxiety/depression to report time burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with anxiety/depression would report greater time burden than those caring for CSHCN without anxiety/depression.

Table 6

Logistic Regression Estimating Time Burden

Variable	B	SE	Odds ratio
Gender: Female***	0.045	0.046	1.046
Race/Ethnicity: Other Race (Not White)***	-0.472	0.036	0.623
Number of CSHCN in the Home: 2+ CSHCN*	0.105	0.041	1.11
Household Parent's Education Level: HS, Above HS***	-0.452	0.028	0.636
Child's Chronic Pain Level: Low/High***	0.535	0.036	1.708
Child's Behavioral Problem Level: Low/High***	0.457	0.039	1.579
Child's Anxiety/Depression Level: Low/High***	0.461	0.039	1.586

*** Significant difference in p = .000; * Significant difference in p = .01; HS = High School; SE = Standard Error

Financial Burden: Prevalence and Factors Influential to Financial Burden

Prevalence of financial burden (unadjusted). In this sample, 20.1% of the caregivers (n=8,087) of CSHCN reported experiencing financial burden because of expenses related to providing care.

Bivariate associations. Bivariate analyses examined the association between the specific types of functional difficulties of CSHCN and financial burden. For CSHCN, 12.8% of caregivers of children with chronic pain, 23.9% of children with behavioral problems, and 26.6% with anxiety/depression reported financial burden. Significant association was found between the child's chronic pain level and financial burden (Chi square (2, n=39,810) =1219.49, p =.000), child's behavioral problem level and financial burden (Chi square (2, n=38,984) =1208.19, p=.000), and child's anxiety/depression level and financial burden (Chi square (2, n=38,880) =2099.4, p=.000).

Table 7 below also shows the association between other independent variables hypothesized to be associated with caregiver financial burden. More than four of every five female caregivers surveyed (84.3%) reported experiencing financial employment while under one in five males (15.7%) reported experiencing financial burden. The association between gender and financial burden was significant (Chi square (1, n=36,829) = 57.96, p = .000). Also, 67.9% of White caregivers surveyed reported experiencing financial burden compared to 13.2% of the Hispanic caregivers, 9.2% of the Black caregivers and 9.7% of the other category. The association between race and financial burden was significant (Chi square (df=3, n=39,934) =53.44, p=.000). The associations between number of CSHCN in the home and financial burden, and between caregiver's education level and financial burden, were not statistically significant.

Table 7

Relationship Between Key Independent Variables and Financial Burden (FBD)

Factors	**Caregivers of CSHCN not experiencing FBD** (N = 31,847) *%*	**Caregivers of CSHCN experiencing FBD** (N = 8,087) *%*
Gender*** cc		
Female	80.5	84.3
Male	19.5	15.7
Race/Ethnicity***		
Hispanic	10.6	13.2
White, non-Hispanic	70.0	67.9
Black, non-Hispanic	10.1	9.2
Other, non-Hispanic	9.3	9.7
Number of CSHCN in the Home		
1 CSHCN	80.1	79.5
2+ CSHCN	19.9	20.5
Household Parent's Education Level		
Less than High School	5.3	5.3
High School Graduate	15.0	14.5
More than High School	79.7	80.2
Child's Chronic Pain Level***		
High	4.4	12.8
Low	19.4	27.9
None	76.3	59.3
Child's Behavioral Problem Level***		
High	11.0	23.9
Low	23.2	28.8
None	65.8	47.2
Child's Anxiety/Depression Level***		
High	10.1	26.6
Low	27.0	35.4
None	62.9	38.0

Note: FBD, financial burden; *** Significant difference in p = .000
"cc" denotes use of continuity correction; other differences were tested using Pearson Chi-Square Tests.

Multivariate model of financial burden. A logistic regression test was run to allow for consideration of the relative effect of key independent variables (caregiver gender, race/ethnicity, caregiver education level, number of CSHCN, child's chronic pain, child's behavioral problems, and child's anxiety/depression) on financial burden when adjusted for other potential covariates (female, non-White race, greater than one CSHCN, low/high chronic pain, low/high behavior problems, and low/high anxiety/depression). The overall model was significant (Chi square=2188.02, p=.000) with a Nagelkerke r square of .093. Table 8 below shows the results.

First, caregiver gender was statistically significant (p=.000). Female caregivers were 1.195 times more likely than males to report financial burden, when adjusted for other covariates. This result was consistent with hypotheses that female caregivers would report greater financial burden than male counterparts.

Second, race/ethnicity was statistically significant (p=.000). Caregivers of color were .898 as likely as White caregivers to report financial burden, when adjusted for other covariates. This finding was contrary to the hypothesis expecting that greater financial burden would be reported among caregivers of color as compared to White caregivers.

Third, although the overall model was significant in estimating financial burden, contrary to hypotheses, the relative effect of the number of CSHCN cared for in the home was not statistically significant.

Fourth, caregiver education level was significant (p=.000) when adjusted for other covariates. Increased education was found to decrease odds of caregivers experiencing financial burden.

Fifth, child's chronic pain level was also statistically significant (p=.000). Caregivers of CSHCN with any chronic pain were 1.789 times more likely than caregivers whose CSHCN had no chronic pain to report financial burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with chronic pain would report greater financial burden than those caring for children without chronic pain.

Sixth, child's behavioral problem level was also statistically significant (p=.000). Caregivers of CSHCN with any behavior problems were 1.521 times more likely than caregivers whose CSHCN had no behavioral problems to report financial burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with behavioral problems would report greater financial burden than those caring for CSHCN without behavioral problems.

Lastly, child's anxiety/depression level was statistically significant (p=.000). Caregivers of CSHCN with any anxiety/depression were 2.106 times more likely than caregivers whose CSHCN had no anxiety/depression to report financial burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with anxiety/depression would report greater financial burden than those caring for CSHCN without anxiety/depression.

Table 8

Logistic Regression Estimating Financial Burden

Variable	β	SE	Odds ratio
Gender: Female***	0.178	0.037	1.195
Race/Ethnicity: Other Race (not White)***	-0.107	0.03	0.898
Number of CSHCN in the Home: 2+ CSHCN	-0.041	0.034	0.960
Household Parent's Education Level: HS, Above HS***	0.157	0.027	1.17
Child's Chronic Pain Level: Low/High***	0.582	0.029	1.789
Child's Behavioral Problem Level: Low/High***	0.419	0.031	1.521
Child's Anxiety/Depression Level: Low/High***	0.754	0.031	2.106

*** Significant difference in p = .000; HS = High School; SE = Standard Error

Employment Burden: Prevalence and Factors Influential to Employment Burden

Prevalence of employment burden (unadjusted). In this sample, 31.8% of the caregivers (n=12,808) of CSHCN reported experiencing employment burden because of providing care.

Bivariate associations. Bivariate analyses examined the association between the specific types of functional difficulties of CSHCN and employment burden. For CSHCN, 9.7% of caregivers of children with chronic pain, 20.6% of children with behavioral problems, and 22.5% of children with anxiety/depression reported employment burden. Significant association was found between the child's chronic pain level and employment burden (Chi square (2, n=39,865) =717.05, p=.000), child's behavior problem level and employment burden (Chi square (2, n=39,040) =1049.58, p=.000), and child's anxiety/depression level and employment burden (chi square (2, n=38,938) =1934.8, p=.000).

Table 9 below also shows the association between other independent variables hypothesized to be associated with caregiver employment burden. While 84% of female caregivers surveyed reported experiencing employment burden, 16% of males reported experiencing employment burden. The relationship between gender and employment burden was significant (Chi square (1, n=36,884) =88.55, p=.000). Also, 66.9% of White caregivers surveyed reported experiencing employment burden compared to 13.8% of Hispanic caregivers, 10% of the other category, and 9.3% of Black caregivers. The association between race and employment burden was significant (Chi square (3, n=29,991) =158.12, p=.000). The associations between number of CSHCN in the home and employment burden, and between caregiver's education level and employment burden, were not statistically significant.

Table 9

Relationship Between Key Independent Variables and Employment Burden (EBD)

Factors	**Caregivers of CSHCN not experiencing EBD** (N = 27,183) %	**Caregivers of CSHCN experiencing EBD** (N = 12,808) %
Gender*** cc		
Female	79.9	84.0
Male	20.1	16.0
Race/Ethnicity***		
Hispanic	9.8	13.8
White, non-Hispanic	70.8	66.9
Black, non-Hispanic	10.3	9.3
Other, non-Hispanic	9.1	10.0
Number of CSHCN in the Home		
1 CSHCN	80.1	79.7
2+ CSHCN	19.9	20.3
Household Parent's Education Level		
Less than High School	5.3	5.3

High School Graduate	15.2	14.3
More than High School	79.5	80.3
Child's Chronic Pain Level***		
High	4.3	9.7
Low	19.2	25.2
None	76.5	65.1
Child's Behavioral Problem Level***		
High	10.4	20.6
Low	22.7	27.7
None	66.9	51.7
Child's Anxiety/Depression Level***		
High	9.2	22.5
Low	26.2	34.0
None	64.6	43.5

Note: EBD, employment burden; *** Significant difference in p = .000

"cc" denotes use of continuity correction; other differences were tested using Pearson Chi-Square Tests.

Multivariate model of employment burden. A logistic regression test was run to allow for consideration of the relative effect of key independent variables (caregiver gender, race/ethnicity, caregiver education level, # of CSHCN, child's chronic pain, child's behavioral problems, and child's anxiety/depression) on employment burden when adjusted for potential covariates (female, non-White race, greater than one CSHCN, low/high chronic pain, low/high behavioral problems, low/high anxiety/depression). The overall model was significant (Chi square = 2061.7, p=.000) with a Nagelkerke r square of .08. Table 10 below shows the results.

First, caregiver gender was statistically significant (p=.000). Female caregivers were 1.226 times more likely than males to report employment burden, when adjusted for other covariates. This result was consistent with hypotheses that female caregivers would report greater employment burden than male counterparts.

Second, race/ethnicity was also statistically significant (p=.000). Caregivers of color were .808 as likely to report employment burden when adjusted for other covariates. This finding was contrary to the hypothesis expecting that supposed greater employment burden would be reported among caregivers of color as compared to White caregivers.

Third, although the overall model was significant in estimating employment burden, contrary to hypotheses, the relative effect of the number of CSHCN was not statistically significant.

Fourth, caregiver education level was significant (p=.000) when adjusted for other covariates. Increased education was found to decrease the odds of caregivers experiencing employment burden.

Fifth, child's chronic pain level was also statistically significant (p=.000). Caregivers of CSHCN with any choric pain were 1.467 times more likely than caregivers whose CSHCN had no chronic pain to report employment burden when adjusted for other covariates This result was consistent with hypotheses that caregivers of children with chronic pain would report greater employment burden than those caring for CSHCN without chronic pain.

Sixth, child's behavioral problem was significant (p=.000). Caregivers of CSHCN with any behavioral problems were 1.4 times more likely than caregivers whose CSHCN had no behavioral problems to report employment burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with behavioral problems would report greater employment burden than those caring for CSHCN without behavioral problems.

Lastly, child's anxiety/depression was also statistically significant (p=.000). Caregivers of CSHCN with any anxiety/depression were 1.975 times more likely than caregivers whose CSHCN had no anxiety/depression to report employment burden, when adjusted for other covariates. This result was consistent with hypotheses that caregivers of children with anxiety/depression would report greater employment burden than those caring for CSHCN without anxiety/depression.

Table 10

Logistic Regression Estimating Employment Burden

Variable	β	SE	Odds ratio
Gender: Female***	0.203	0.031	1.226
Race/Ethnicity: Other Race (not White)***	-0.213	0.026	0.808
Number of CSHCN in the Home: 2+ CSHCN	-0.052	0.029	0.95
Household Parent's Education Level: HS, Above HS***	0.136	0.023	1.146
Child's Chronic Pain Level: Low/High***	0.383	0.026	1.467
Child's Behavioral Problem Level: Low/High***	0.336	0.027	1.4
Child's Anxiety/Depression Level: Low/High***	0.681	0.026	1.975

*** Significant difference in p = .000; HS = High School; SE = Standard Error

CHAPTER V

Discussion

Within the 2009-2010 NS-CSHCN sample and consistent with research questions, caregiver gender and race/ethnicity were both found to be significantly associated with time, financial, and employment burden reportedly experienced by caregivers of CSHCN. Additionally, education level and the number of CSHCN in the household were found to be significantly related to time burden. Also confirming research questions pertaining to specific types of functional difficulties that CSHCN experience, child's chronic physical pain, behavior problems, and anxiety/depression level were all significantly related to time, financial, and employment burden, which is a novel addition to this field of interest. These findings generally support existing literature suggesting that these family characteristics have an impact on the lives of caregivers of CSHCN. The large sample size of the NS-CSHCN is representative and the characteristics of the sample are likely distributed equally to that of the overall population with regards to sociocultural factors. Because of this, the study's strengths include its external validity suggesting the discovered associations hold greater generalizability than studies of smaller sample size or less geographic reach.

Contributions to Extant Literature

Below, the findings of this study are compared to prior literature, highlighting key implications for social work practice, policy, and theory. Later, recommendations will be made for future research.

Time burden. Regarding time burden, Miller et al.'s (2015) research found higher time burden among non-White caregivers with low adult education in the 2009-2010 NS-CSHCN. The current study confirmed these findings on education, however found a contrary finding in relation to race/ethnicity. This discrepancy may be explained by the way that the current study operationalized racial categories and the choice to simplify racial categories into only White and not White for multivariate modeling. This decision was made due to low percentages in the Hispanic, Black, and other categories, which may be accounted for by the way that the current study excluded participants whose responses were recorded as "don't know" or "refuse to answer" in the pertinent survey sections. This binary categorization also did not allow for an acknowledgement of caregivers who may have identified as multiracial.

Based on the current findings, of those caregivers who reported experiencing time burden, approximately three quarters (77.6%) had one CSHCN while just under a quarter (22.4%) had two or more CSHCNs. As hypothesized the association between number of CSHCN in the home and time burden was significant, however it was hypothesized that having fewer CSHCN would be associated with lower odds of experiencing time burden. Research outside of the NS-CSHCN has examined parenting stress specifically among mothers of children with different physical, mental, and psychological problems finding that mothers with one child that had chronic physical ailments scored higher on measures of parent-child dysfunctional interactions than those with other numbers of children (Feizi, Najmi, Salesi, Chorami, & Hoveidafar, 2014). Perhaps there is an element of exposure to the systems of care that CSHCN and their families find themselves in, and that the addition of more children to that system may promote mastery, at times, as opposed to increase stress and time burden in providing and coordinating care.

Financial burden. Related to financial burden, Kuhlthau et al. (2005) stated that 40% of families with CSHCN reported experiencing financial burden related to their child's medical condition through the 2000-2002 NS-CSHCN. The current study (2009-2010 data) as well as the 2009-2010 NS-CSHCN chartbook, reported that about 20% of respondents (n=8,087) endorsed experiencing financial burden due to their child's condition. This provides preliminary evidence of a trend over time of decreasing time burden within this specialized population. On the other hand, Ghandour et al. (2014) reported increases in financial burden between 2001 and 2009. As such, more research should be done to clarify these trends and continue to track any significant findings longitudinally.

The current study also found that for CSHCN, chronic pain, behavioral issues, and anxiety/depression were all significantly associated with financial burden through bivariate analyses. Of those CSHCN who experienced any anxiety/depression, 26.6% had caregivers who also endorsed financial burden. This finding suggests that caregivers who are seeking mental health services for their CSHCN with this specific functional difficulty may be met with more barriers related to affordability and overall accessibility from a financial standpoint than caregivers seeking other services. This evidence of differential financial burden for these caregivers remained true when adjusted for other covariates, and as such caregivers of CSHCN with anxiety/depression were 2.106 times more likely to experience financial burden than their counterparts.

Employment burden. In terms of employment burden reported by caregivers of CSHCN, the current study supplemented findings by Ghandour et al. (2014) by once again examining race/ethnicity and child's condition severity indicators as covariates adjusted for in estimating odds of experiencing employment burden. In the multivariate model run to predict employment burden, race/ethnicity as well as the presence of a child's chronic pain, behavioral problems, and anxiety/depression were all statistically significant. Ghandour et al. (2014) had also found that the experience of caregiver employment burden can be mediated by the severity of the child's condition. The multivariate analyses in this study grouped severity with regards to functional difficulties into two groups: no difficulty and those who reported either low or high difficulty. A spectrum of severity is unable to be deciphered with this chosen method, however the finding that caregivers of CSHCN with chronic pain, behavioral problems, and anxiety/depression all had statistically significant increased odds of reporting employment burden compared to caregivers of CSHCN without any of those difficulties certainly paves the way for future research in this area.

Implications for Clinical Social Work Practice

The current study has revealed novel caregiver, child, and systemic influences that impact the prevalence of burden, which could be helpful in creating more targeted, specific, and effective interventions. As related to practitioners who provide care for CSHCN and their families, the results indicating the high prevalence of time, financial, and employment burden reported by caregivers of CSHCN suggest that one way to improve care may be to simply acknowledge and appreciate the various sacrifices and challenges that the entire family system around the CSHCN may be experiencing. As previous literature suggests (i.e. Yee and Shulz, 2000), feeling burdened by caregiving has serious physical and psychological consequences, and therefore being more aware and paying attention to these issues is important for the field as a whole.

Social workers may also be helpful in being highly knowledgeable in local resources that could save families time in independently seeking them out. It also seems important for clinicians to be aware of the statistics that within this population female caregivers are 1.046

times more likely to report time burden, 1.195 times for financial burden, and 1.226 times for employment burden than male caregivers. Based on this, it is imperative that clinicians provide adequate emotional support that is reflective and demonstrates an empathic awareness of this issue and disproportionate impact. Additionally, clinicians who may be working with CSHCN should also be mindful that caregivers' reports of high burden may have various consequences on the home environment that could be impacting the child's experience in a variety of ways.

In this study, it was found that contrary to hypotheses, caregivers of color were .623 as likely as White caregivers to report time burden, .898 as likely as to report financial burden, and .808 as likely to report employment burden all when adjusted for other covariates. Frequency analyses of the sample also showed that a majority of the sample (69.6%) identified as White. These findings were all contrary to hypotheses based on previous literature (i.e. Miller et al., 2015) that caregivers of color would overall experience more burden than White counterparts due to disparities in the physical and mental health fields that affect access and treatment. While methodology and the operationalization of variables in this study may account for these differences in findings, there may also be an effect of people of color underreporting experiences of burden related to finding, paying for, and accessing services for CSHCN due to embedded experiences and knowledge that services are not and will not be accessible of beneficial to them in many communities. This is an important consideration for clinical social workers who are on the front lines of providing care to diverse populations, and as such can make efforts to ensure that practice is welcoming, culturally informed, and accessible.

Research along these lines has been reported by Cai and Robst (2016), who concluded that people who identified as African American or Hispanic had more negatively perceived experiences of their mental health care. Furthermore, suggestions were made that "efforts should be undertaken in the mental health field to improve minority patients' perceptions of care. Cultural sensitivity education for both mental health service providers and staff members would lead to more positive minority patient perceptions of quality and communication" (Cai & Robst, 2016, p. 516). It is the responsibility of providers and the agencies that they work in to help achieve these outcomes.

Implications for Policy

By using national estimates and a nationally representative sample to understand both the depth and breadth of the issues affecting families and caregivers of CSHCN, the implications for policy is particularly useful on the federal level. As such, any results may have more leverage to create legislation that supports these families or to improve on existing federal services and programs such as Supplemental Security Income (SSI), the Affordable Care Act (ACA), Medicare, and Title V: Maternal and Child Health Services Block Grant Program. SSI provides financial support to people with disabilities who have limited income, which for families who qualify, likely decreases the likelihood of financial burden attributable to caring for a CSHCN. Because 20.1% (n=8,807) of this sample reported experiencing financial burden, one policy implication is that efforts to lower income or illness severity thresholds for SSI eligibility could help decrease the percentage of caregivers experiencing financial burden nationwide. Research like this and having critical conversations around this topic are especially important in the era today in which budget cuts and support for services like SSI have been threatened.

By identifying the populations most at risk for developing burden and by producing explicit interventions that help meet the needs of these people, policymakers will be able to prevent long-term negative outcomes for CSHCN and their families. The current study's findings suggest that those most likely to experience financial burden are White female caregivers with lower levels of education. Across all types of caregiver burden studied, the highest odds ratio for the child's type of functional difficulty was found for caregivers of CSHCN with anxiety/depression. For financial burden, caregivers of CSHCN with any anxiety/depression were 2.106 times more likely than caregivers whose CSHCN had no anxiety/depression to report financial burden when adjusted for other covariates, which was one of the highest odds ratios reported. This statistic provides evidence that on a broader scale, there may be an especially large financial cost attached to finding psychiatric services for youth.

This statistic, coupled with the finding that 41% of the survey respondents reported some amount of anxiety/depression affecting the functioning of their CSHCN, it follows that policy initiatives aiming to decrease the cost of mental health, psychiatry services, or alternative treatments for anxiety/depression would be very useful for this population. It also highlights the importance of programs such as Early Intervention services, which support social and emotional wellness in children birth to three years old, continuing to be funded by the federal government. While geographic location and insurance coverage were beyond the scope of this investigation, research has shown that some of the state-to-state variability in how much low-income families of CSHCN are paying out-of-pocket for services can be explained by differences in the states' income eligibility requirements for public health insurance, and ultimately that families in states with more liberal benefits report less financial burden (Parish, Shattuck, & Rose, 2009).

In this vein of research, there are existing initiatives with missions of better understanding and more robustly attending to the needs of families and CSHCN. For example, Project Impact, run through Boston University's School of Public Health and the Catalyst Center, aims to "engage Federal, state, and community stakeholders and partners in ensuring the implementation of the ACA and other health care delivery financing efforts address the needs of CYSHCN [children and youth with special health care needs]" (Center for Advancing Health

Policy and Practice, 2017). Overall, policymakers can help CSHCN by supporting legislative initiatives that improve care and access to services and programs that aim to decrease family burden within this population.

One service that may be important to consider in attaining this outcome is the implementation of Health Care Homes, which have been found to assist caregivers of CSHCN to cope more effectively (Drummond et al., 2012) and to decrease the odds of caregivers of CSHCN experiencing time burden (Miller et al., 2015). Medicaid, which is directed to states according to federal requirements, provides guidelines on defining health home services, developing health home population criteria, and integrating physical and behavioral health within health homes (Medicaid.gov). These guidelines suggest that each state should individually define who the beneficiaries of health homes should be to maximize the effect that the program has within the state.

Based on the findings of the current study, states may want to prioritize families with female heads of households or single mothers, as female caregivers of CSHCN have been found to be at increased odds and have especially high risk for experiencing burden. As such, a health home intervention may be especially impactful for this population. The current study's findings also reinforce the importance of integrating care for both physical (i.e. chronic pain) and behavioral (i.e. behavioral conduct issues, anxiety/depression) health as a means of addressing complex care needs for families of CSHCN. Accordingly, individual states must work flexibly within their leeway for defining provider qualification for a health home. They must prioritize effective incorporation of services that address both physically and behaviorally based challenges. This endeavor could potentially require increased oversight and policy changes to state freedom on the federal level. Also, because a health care home provides each enrolled family with an ongoing relationship with a health care professional, medical social workers may be on the front lines of assessing program effectiveness, advocating for proper implementation, supporting families as they need to engage with other community social services, and overall communicating across the integrated care experience. For this reason, hospitals and other health care settings likely need to adjust their own policies and provide more specific training, support, and incentive to these medical social workers.

Implications for Theory

The main theoretical frameworks that informed the current study were systems theory and transactional stress theory, both of which consider the ways that burden can be a product of factors at multiple levels of human experience and interpersonal dynamics. These theoretical lenses also help to explain the co-dependence and enmeshment that often stems from a caregiver-care recipient relationship as well as the ways in which stress in the environment or in one part of a system can ripple into other parts of the system, with burden being a possible byproduct of this process.

The results of the current study provide evidence to support the relevance of systems theory in this line of research. As systems theory posits, the current study found statistically significant associations between burden (time, financial, and employment) and factors on multiple components of a family system. For example, among other bivariate associations, there was a significant relationship between caregiver gender and burden (time, financial, and employment), between caregiver education level and time burden, between the number of CSHCN in the home and time burden, and a child's type of functional difficulty and burden (time, financial, and employment). These results also provide evidence of the interconnectedness of person and environment as in Transactional Stress Theory, however future longitudinal cohort studies that can establish directional causality would be necessary to further apply and understand the theory in this context.

Based on the implications and results of the current study, new theoretical concepts and contexts may also be interesting to explore. One avenue for this may be the concept of attachment theory. Due to the significant relationship between types of the functional difficulty of the CSHCN (chronic pain, behavioral problems, anxiety/depression) and types of burden measured by this study, it may be interesting to see if there are also relationships between one's attachment style coupled with the type of functional difficulty and caregiving burden. Outside of the CSHCN population, this has been examined asking how the attachment styles of adult children and their older parents predict perceptions of caregiver burden, finding for example that attachment avoidance was positively correlated with burden (Karantzas, Evans, & Foddy, 2010).

Limitations and Recommendations for Future Research

Despite the clearly beneficial findings of the current study, there are certainly limitations that make way for opportunities for future research. For example, this study focuses strictly on responses from the 2009-2010 NS-CSHCN and only on home-based children. As such, it does not capture any changes over time, the most recent state of the nation on these issues, or the experiences of any CSHCN who reside in institutions such as schools or hospitals. Although the current study suggests a model for the ways in which characteristics in multiple domains of a family's experience are related to reported occurrences of time, financial and employment burden, which ultimately acknowledges some level of causality within this model, the chosen methodology and lack of longitudinal data prevent these assumptions. Bivariate analyses were run with chi-square tests, which while important in determining whether there is a relationship between two variables, but do not reveal the strength of any such relationship. Multivariate regressions allowed for the control of each covariate to parse out the individual effect of each of the independent variables on caregiver burden. Within these findings, this study reported standard error, although confidence intervals would have been preferred. The latter was unable to be achieved within the constraints of working with a data analyst.

Also due to time limitations, analyses of the current data were not able to include interaction terms of factors such as race and gender, which would have allowed for further exploration of the key role of multiple identities and the importance of an intersectional lens in this line of study. Future research should specifically study the interaction of race/ethnicity and gender. While multiple chi-square tests on the single variables yielded observed frequencies that were significantly different from what probability would typically expect, future research that is longitudinal in nature can confirm directionality within this proposed model and would be highly beneficial area of further interest to the field.

It is important to note the disproportionate representation of women in the sample, which may have implications for this line of research. Although this is a national data set, frequency analysis showed that 75% of the total survey respondents (n=30,059) were categorized as female. This proportion does not align with general population norms. It should also be noted that the way in which caregiver gender was operationalized in this study existed on a binary that likely did not capture the experiences of many caregivers who may identify as transgender or gender nonconforming. Additionally, caregiver responses were excluded from analysis of they indicated having a relationship to the CSHCN in question that could not be identified as specifically male or female (i.e. “other relative”) or if they chose not to answer that question.

This study’s findings suggest that being a female caregiver is related to increased odds of experiencing time, financial, and employment burden than male counterparts, in a model adjusted for other potential covariates. While 75% of the general U.S. population is not female, it may be true that 75% of the nation's caretaking duties are carried out by women. It may also be true that the timing of the NS-CSHCN phone calls coincided in some way to parts the day when a majority of male family workers may have been at work. Future research could be done to parse out these differences and test associations of any other covariates that may impact caregiver burden. It would also be interesting and beneficial to the field to engage caretakers who identify as male in research regarding any specific aspects of that identity that are especially hard to navigate or are reported to be burdensome in any number of ways.

Another potential limitation of this study is the way that the dependent variables were operationalized. Although these decisions were informed by existing literature, the choices may not reflect all aspects of caregiver burden experienced by survey participants. As such, diverse research that robustly explores multiple possible definitions of burden would be useful. Aside from the possible misunderstandings on behalf of survey participants, it is important to note that the nature of the NS-CSHCN itself is burdensome. Additionally, within this data set there is no comparison group in which family impact, and derived burden were assessed within a sample of children without special health care needs.

One avenue for future research would be to narrow the scope of the NS-CSHCN survey instrument and focus more specifically, for example, on understanding the unique needs of children with mental health challenges and associated special health care needs. The overall national response rate for the 2009-2010 NS-CSHCN was 80.8% (Center for Disease Control and Prevention, National Center for Health Statistics, State and Local Are Integrated Telephone Survey, 2011). Shortening the length of the survey as well as targeting the audience so the entire survey is relevant and applicable to each respondent may increase completion and fidelity rates and ensure the most accurate reporting. Despite the limitations of the survey instrument itself, using it as the basis of the current study's data source and analyzing it as a secondary data set minimized researcher bias, which makes the study more convincing when looking to confirm aspects of the current research questions and previous literature.

In the United States, 15% of children aged 18 and under are CSHCN. As previous research and this study have shown, the people that care for them often experience various types of burden as a result. Findings here shed light on the significantly greater time, financial, and employment burden being placed on female caregivers of CSHCN as well as on the significant association between CSHCN's functional difficulties and caregiver burden. Because historically disenfranchised groups, namely women, have been shown to experience greater burden, and because there seems to be an underrepresentation of people of color in population health research more broadly, the current study and the results are an important contribution to the field. The prevalence of caregiver burden among families of CSHCN and the increased knowledge regarding the disproportionate impact for families where caregivers are female, have certain levels of education, or care for multiple CSHCN, should inform legislative changes within federal and state policy and should advise clinical social workers to better meet the needs of people from historically disenfranchised communities more susceptible to caregiver burden. As to whether characteristics of the family and CSHCN influence caregiver burden, this research finds that associations do exist requiring additional attention to ways caregiver burden can be addressed in policy and practice.

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Appendix A

SMITH COLLEGE

School for Social Work

Smith College

Northampton, Massachusetts 01063

October 28, 2016

Chelsea Davies

Dear Chelsea,

The Smith College School for Social Work Human Subjects Review Committee approves your request for exemption from SSW Human Subjects Review Committee review based on the study's use of secondary data. We wish you the best with your research.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Tom Mackie, Research Advisor

Appendix B

Measures of Key Variables in Prior Literature – Summary of the Different Approaches

Variable	Measure	Response Set	Study
Time Burden	Caregiving burdens: A family member spent greater than 10 hours providing or coordinating care in the last week considered "high burden."	Assessed using responses to question on care provision and question on care coordination. Measure is a sum of numerical hours reported for each activity.	Ghandour et al., 2014
	Time burden: 3 dependent variables: providing health care for child at home (none/less than 1, 1-5, 6-10, 11+ hours/week), arranging/coordinating care for child (none/less than 1, 1-5, 6-10, 11+ hours/week), first two combined.	Minimal=none/less than 1 combined, low=1-5 or 6-10 on one, none/less than 1 on other or 1-5 on each, moderate=all other combinations except high, high=21+ on either or 11-12 hours on both.	Miller et al., 2015
Financial Burden	Absolute out of pocket expense: families spent greater than or equal to $1,000 out of pocket for health-related needs during prior 12 months considered "high burden."	Assessed by parent-reported expenditures: $0, $1-$249, $250-$500, $501-$999, $1,000-$5,000 and $5,000+.	Ghandour et al., 2014
	Relative out of pocket expense: families spent greater than or equal to 3% of household income on out of pocket health-related needs during prior 12 months, considered "high burden."	Assessed by using midpoint of each expenditure category (see above) Median family income assigned regarding household size, poverty level, and state. Calculated ratio of expenditure to income.	Ghandour et al., 2014
	The child's condition(s) caused financial problems for the family.	Assessed from single dichotomous survey item: "Has the child's health condition caused financial problems for the family? Yes or no?	Ghandour et al., 2014
	Derived from 2 questions -Whether family had financial problems due to child's condition or the family paid $5,000, $1,000-$5,000, or less than $1,000 for medical care excluding insurance premiums.	Categorized into 2 groups: 1-had financial problems/spent greater than or equal to $1,000 and 2-no financial problems/paid less than $1,000 for medical care.	Vohra et al., 2014
	Economic impact as a dependent variable	Assessed by affirmative answer to "has child's health condition caused financial problems for your family - Yes/no?	Looman et al., 2009
Employment Burden	Employment changes: A family member quit or cut back on work because of the child's condition(s).	Assessed by affirmative response to either of 2 dichotomous survey items: "Has a family member cut down on hours? Yes or	Ghandour et al., 2014

		no? Has a family member quit working? Yes or no?	
	Employment burden	Assessed by yes/no response to question “did caregiver stop working because of child’s condition?”	Vohra et al., 2014
	Impact on employment	Assessed by affirmative yes/no answer to one or both of following questions: “Have you or other family members cut down on hours? Stopped working?	Looman et al., 2009
Race/Ethnicity	As described in NS-CSHCN screener.	Race/ethnicity used as possible covariate.	Ghandour et al., 2014
	As described in NS-CSHCN screener.	Child’s race and ethnicity used as independent variable, 4 categories: non-Hispanic Whites, Blacks, Other races, any Hispanic race.	Vohra et al., 2014
# of CSHCN in home	As described in NS-CSHCN household file.	# of special needs children, as independent variable, 2 categories: 1, more than 1.	Vohra et al., 2014
Mental Health Indicators	Child’s special needs condition used as key independent variable.	Separated into categories: ASD (Autism, Asperger's disorder, pervasive developmental disorder, other autism spectrum disorder), DD (cerebral palsy, Down syndrome, developmental delay, ID or IDD), MHC (ADHD, anxiety, behavioral/conduct problems, depression). From this distinction created hierarchical classification: 1-ASD, 2-DD w/o ASD or MHC, 3-MHC w/o ASD or DD, 4-both DD and MHC w/o ASD.	Vohra et al., 2014.
	Child’s functional ability as independent variable.	3 categories: never affected, sometimes/very little affected, always/usually affected.	Vohra et al., 2014
	Severity of child’s condition	Assessed on scale 0-10, “How would you rank the severity?”	Looman et al., 2009
Composite Variables	Any burden	High absolute out of pocket expenses + financial problems + employment changes + caregiving (time) burdens.	Ghandour et al., 2014
	“Family Impact” as dependent variable.	Financial burden + employment burden + time-related burden.	Vohra et al., 2014
	Socioeconomic Status	Caregiver income level (less than or equal to 100%FPL, 101%-200% FPL, 201%-400% FPL, and greater than 400% FPL) + caregiver education level (less than HS, HS, greater than HS.	Vohra et al., 2014

Appendix C

Domains and Variables in NS-CSHCN Interview

Domain	Variable # - Variable (instrument); *variable name*	Response Set (Value)
Financial Burden	439 - Have child's health conditions caused financial problems for your family? (interview); *C9Q05*	Yes (1) No (0) Don't Know (6) Refused (7)
	107 - During the past 12 months/ since birth, did you have any difficulties or delays b/c of issues related to cost? (interview); *C4Q03_D*	Yes (1) No (0) Don't know (6) Refused (7)
	235 - 251 - Why did child not get all the mental health care or counseling they needed? (interview); *C4Q05_6BR01*	**Cost was too much (1)** No insurance (2) Health Plan Problem (3) Can't find provider who accepts child's insurance (4) Not avail. in area/transport problems (5) Not convenient times/could not get appointment (6) Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9) Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don't know (77) Refused (99)
	331- 350 - Family did not get all the mental health care or counseling they needed b/c cost was too much (interview); *C4Q06_3BR01*	**Cost was too much (1)** No insurance (2) Health Plan Problem (3) Can't find provider who accepts child's insurance (4) Not avail. in area/transport problems (5) Not convenient times/could not get appointment (6) Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9)

		Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don't know (77) Refused (99)
	432 - Are the costs not covered by child's health insurance reasonable? (interview); *C8Q01_B*	Never (1) Sometimes (2) Usually (3) Always (4) No out of pocket costs (5) Don't Know (6) Refused (7)
	434 - During the past 12 months/ since child's birth, would you say that the family paid more than $500, $250-$500, less than $250, or nothing for child's medical care? (interview); *C9Q01*	More than 500 (1) 250-500 (2) Less than 250 (3) Nothing (4) Don't Know (6) Refused (7)
	435 - During the past 12 months/since their birth would you say that family paid more than $5,000, $1,000-$5,000, or less than $1,000 for child's medical care? (interview); *C9Q01_A*	More than 5000 (1) 1000-5000 (2) Less than 1000 (3) Don't know (6) Refused (7)
Time Burden	436 - Do you or other family members provide health care at home for child? (interview); *C9Q02*	No (0) Yes (1) Don't know (6) Refused (7)
	437 - How many hrs./week do you or other family members spend providing this kind of care? (interview); *C9Q03*	N hours/week (N) Less than 1 hour (000) Around the clock (168) Don't know (996) Refused (997) *Range 000-168, 996, 997
	438 - How many hrs./week do you or other family members spend arranging or coordinating child's care? (interview); *C9Q04*	N hours/week (N) Less than 1 hour (000) Around the clock (168) Don't know (996) Refused (997) *Range 000-168, 996, 997
	235 - 251 - Why did child not get all the mental health care or counseling they needed? (interview); *C4Q05_6B*	Cost was too much (1) No insurance (2) Health Plan Problem (3) Can't find provider who accepts child's insurance (4)

		Not avail. in area/transport problems (5) **Not convenient times/could not get appointment (6)** Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9) Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don't know (77) Refused (99)
Employment Burden	440 - Have you or other family members stopped working because of child's health? (interview); *C9Q10*	No (0) Yes (1) Don't know (6) Refused (7)
	441 - Have you or other family members cut down on the hours you work because of child's health conditions? (interview); *C9Q06*	No (0) Yes (1) Don't know (6) Refused (7)
	442 - have you or other family members avoided changing jobs because of concerns about maintaining health insurance for child? (interview); *C9Q11*	No (0) Yes (1) Don't know (6) Refused (7)
Emotional Burden	110 - During the past 12 months/since birth, how often have you been frustrated in your efforts to get services for child? (interview); *C4Q04*	Never (1) Sometimes (2) Usually (3) Always (4) Don't know (6) Refused (7)
	291 - During the past 12 months/since birth, was there any time when you or other family members needed respite care? (interview); *C4Q06_1*	No (0) Yes (1) Don't know (6) Refused (7)
	331 - During the past 12 months/ since child's birth, was there any time when you or other family members needed mental health care or counseling related to child's medical, behavioral, or other mental health conditions? (interview); *C4Q06_3*	No (0) Yes (1) Don't know (6) Refused (7)
	332- Did you or your family member receive all the mental health care or counseling that was needed? (interview) *C4Q06_3A*	No (0) Yes (1) Don't know (6)

		Refused (7)
	350 - Did you or your family get any mental health care or counseling during past 12 months/ since child's birth? (interview); C*4Q06_3C*	No (0) Yes (1) Don't know (6) Refused (7)
Income/ Socioeconomic Status (SES)	484 - At any time during the past 12 months, even for 1 month, did anyone in this household receive any cash assistance from a state or county welfare program? (interview); *C11Q11*	No (0) Yes (1) Don't know (6) Refused (7)
	409 - At this time, is child covered by any Medicaid plan? (interview); *C7Q01*	No (0) Yes (1) Don't know (6) Refused (7)
	85 - Does child receive SSI? (interview); *C11Q12*	No (0) Yes (1) Don't know (6) Refused (7)
Geographic Location	3 - State of Residence (interview); *LOC_STATE*	Drop down menu, 50 States & DC
	105 - During the past 12 months/ since birth, did you have any difficulties or delays b/c the services child needed were not available in your area? (interview); *C4Q03_B*	No (0) Yes (1) Don't know (6) Refused (7)
	239 - Child did not get all of the mental health care or counseling they needed b/c not available in area / transport problems (interview); *C4Q05_6B*	Cost was too much (1) No insurance (2) Health Plan Problem (3) Can't find provider who accepts child's insurance (4) **Not avail. in area/transport problems (5)** Not convenient times/could not get appointment (6) Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9) Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don't know (77) Refused (99)

	331- 350 - Family did not get all the mental health care or counseling they needed b/c not available in area/ transport problems (interview); *C4Q06_3B*	Cost was too much (1) No insurance (2) Health Plan Problem (3) Can't find provider who accepts child's insurance (4) **Not avail. in area/transport problems (5)** Not convenient times/could not get appointment (6) Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9) Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don't know (77) Refused (99)
Immigration	476 - Was child's mother born in U.S? (interview); *K11Q30*	No (0) Yes (1) Don't know (6) Refused (7)
	477 - Was child's father born in the U.S? (interview); *K11Q31*	No (0) Yes (1) Don't know (6) Refused (7)
	478 - Were you born in the U.S.? (non-parent respondent) (interview); *K11Q32*	No (0) Yes (1) Don't know (6) Refused (7)
	479 - Was child born in the U.S? (interview); *K11Q33*	No (0) Yes (1) Don't know (6) Refused (7)
	480 - How long has mother been in the U.S? - standardized to years (interview); *K11Q34A*	N (N) Don't know (996) Refused (997) *K11Q34B Marks period: Days (1) Weeks (2) Months (3) Years (4)
	481- How long has father been in the U.S? - standardized to years (interview); *K11Q35A*	N (N) Don't know (996)

		Refused (997) *K11Q35B Marks period: Days (1) Weeks (2) Months (3) Years (4)
	482 - how long have you been in the U.S.? (non-parent respondent)- standardized to years (interview); K*11Q36*	N (N) Don't know (996) Refused (997) *K11Q36B Marks period: Days (1) Weeks (2) Months (3) Years (4)
	483 - how long has child been in the U.S.? - standardized to years (interview); *K11Q37*	N (N) Don't know (996) Refused (997) *K11Q37B Marks period: Days (1) Weeks (2) Months (3) Years (4)
Age	57 - how old was child when a Dr. or other HCP first told you that they had autism or ASD? (age) (interview); *K2Q35D*	N Years (N) Don't know (96) Refused (97) K2Q35DA: Months (1) Years (2)
	353 - How old was child when they first began receiving special education services? (interview); *C3Q13A*	N Years (N) Don't know (96) Refused (97) C3Q13AA: Months (1) Years (2)
	8 - During the past 12 months/ since their birth, how often have child's medical, behavioral, or other health conditions / emotional, developmental, or behavioral problems affected their ability to do things other children their age can do? (interview); *C3Q02*	Never (1) Sometimes (2) Usually (3) Always (4) Don't know (6) Refused (7)
Severity of SCHC	9 - Do child's medical, behavioral, other conditions affect their ability to do things a great deal, some, or very little? (Interview); *C3Q03*	A great deal (1) Some (2) Very Little (3) Don't know (6) Refused (7)
	84 - During the past 12 months, about how many days did child miss school because of illness or injury? (interview); *C3Q14R*	N number of days (N) None (000) Didn't go to school (994)

		Home schooled (995) Don’t know (996) Refused (997)
	85 - Do child’s medical, behavioral, or other health conditions/ emotional, developmental or behavioral problems, interfere with their ability to attend school on a regular basis? (interview); *C3Q40*	No (0) Yes (1) Don’t know (6) Refused (7)
	86 - ‘ ‘ ‘ ‘ participate in sports, clubs, or other organized activities? (interview); *C3Q41*	No (0) Yes (1) Don’t know (6) Refused (7)
	87 - ‘‘ ‘ ‘ participate in play w/other children? (interview); *C3Q42*	No (0) Yes (1) Don’t know (6) Refused (7)
	88 - ‘ ‘ ‘ ‘ go on outings, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings? (interview); *C3Q43*	No (0) Yes (1) Don’t know (6) Refused (7)
	89 - during the past 12 months/ since child’s birth, was child admitted to a hospital overnight? (interview); *C3Q50*	No (0) Yes (1) Don’t know (6) Refused (7)
	233 - During the past 12 months/ since child’s birth, was there any time when child needed mental health care or counseling? (interview); *C4Q05_6*	No (0) Yes (1) Don’t know (6) Refused (7)
	252 - Did child get any mental health care or counseling during the past 12 months/ since birth? (interview); *C4Q05_6C*	No (0) Yes (1) Don’t know (6) Refused (7)
	351 - does child receive services from a program called Early Intervention Services? (interview); *C3Q12*	No (0) Yes (1) Don’t know (6) Refused (7)
	468 - At any time during the past 12 months, did child receive behavioral treatment for ADD or ADHD, such as classroom management, peer interventions, social skills training, or CBT? (interview); *C95Q03*	No (0) Yes (1) Don’t know (6) Refused (7)
	352 - does child receive services from a program called Special Education services? (interview); *C3Q13*	No (0) Yes (1) Don’t know (6) Refused (7)

Caregiver Relationship	7 - Respondent's relation to selected child (interview); *RELATIONR/C10Q02A*	Bio mother (01) Stepmother (02) Foster mother (03) adoptive mother (04) Mother type refuse (05) bio father (06) stepfather (07) foster father (08) adoptive father (09) father type refuse (10) grandmother (11) grandfather (12) aunt (13) uncle (14) female guardian (15) male guardian (16) sister-any kind (17) brother-any kind (18) cousin (19) in-law any type (20) other rel/fam mem (22) parent's bf/male par (23) parent's gf/fem part (24) parents part (sex ref) (25) other non-rel/friend (26) Don't know (96) Refused (97)
Service Type & Utilization	22 - compared to other same age children, would you say they experience a lot, a little, or no difficulty w/ feeling anxious or depressed? (Interview); *C3Q32*	A lot of difficulty (1) A little difficulty (2) No difficulty (3) Don't know (6) Refused (7)
	23 - compared to other same age children, would you say they experience a lot, a little, or no difficulty w/ behavior problems, such as acting out, fighting, bullying, or arguing? (interview); *C3Q33*	A lot of difficulty (1) A little difficulty (2) No difficulty (3) Don't know (6) Refused (7)
	27 - has a Dr or other HCP ever told you that child had ADD or ADHD? (interview); *K2Q31A*	No (0) Yes (1) Don't know (6) Refused (7)
	28 - ' ' ' ' depression? (interview); *K2Q32A*	No (0) Yes (1) Don't know (6) Refused (7)
	29 - ' ' ' ' anxiety problems? (interview); *K2Q33A*	No (0) Yes (1) Don't know (6) Refused (7)

	30 - ‘ ‘ ‘ ‘ behavioral or conduct problems, such as ODD or conduct disorder? (interview); *K2Q34A*	No (0) Yes (1) Don’t know (6) Refused (7)
	31 - ‘ ‘ ‘ ‘ autism, Asperger’s disorder, pervasive developmental disorder, or other ASD? (interview); *K2Q35A*	No (0) Yes (1) Don’t know (6) Refused (7)
	32 - ‘ ‘ ‘ ‘ developmental delay that affects their ability to learn? (interview); K*2Q36A*	No (0) Yes (1) Don’t know (6) Refused (7)
	3 - ‘ ‘ ‘ ‘ intellectual disability or mental retardation? (interview); *K2Q37A*	No (0) Yes (1) Don’t know (6) Refused (7)
Specific Child Mental Health Indicators & Insurance	47 - Does child currently have ADD or ADHD? (interview); *K2Q31B*	No (0) Yes (1) Don’t know (6) Refused (7)
	48 - Would you describe their ADD or ADHD as mild, moderate, or severe? (interview); *K2Q31C*	Mild (1) moderate (2) severe (3) Don’t know (6) Refused (7)
	49 - Does child currently have depression? (interview); K*2Q32B*	No (0) Yes (1) Don’t know (6) Refused (7)
	50 - would you describe their depression as mild, moderate, or severe? (interview); *K2Q32C*	Mild (1) moderate (2) severe (3) Don’t know (6) Refused (7)
	51 - does child currently have anxiety problems? (interview); *K2Q33B*	No (0) Yes (1) Don’t know (6) Refused (7)
	52 - would you describe their anxiety problems as mild, moderate, or severe? (interview); *K2Q33C*	Mild (1) moderate (2) severe (3) Don’t know (6) Refused (7)
	53 - does child currently have behavioral or conduct problems? (interview); *K2Q34B*	No (0) Yes (1)

		Don’t know (6) Refused (7)
	54 - would you describe behavioral or conduct problems as mild, moderate or severe? (interview); *K2Q34C*	Mild (1) moderate (2) severe (3) Don’t know (6) Refused (7)
	55 - does child currently have autism or ASD? (interview); K*2Q35B*	No (0) Yes (1) Don’t know (6) Refused (7)
	56 - would you describe autism or ASD as mild, moderate, or severe? (interview); *K2Q35C*	Mild (1) moderate (2) severe (3) Don’t know (6) Refused (7)
	59 - does child currently have developmental delay? (interview); K*2Q36B*	No (0) Yes (1) Don’t know (6) Refused (7)
	60 - would you describe their developmental delay as mild, moderate, or severe? (interview); *K2Q36C*	Mild (1) moderate (2) severe (3) Don’t know (6) Refused (7)
	61 - does child currently have intellectual disability or mental retardation? (interview); *K2Q37B*	No (0) Yes (1) Don’t know (6) Refused (7)
	62 - would you describe their intellectual disability or mental retardation as mild, moderate, or severe? (interview); *K2Q37C*	Mild (1) moderate (2) severe (3) Don’t know (6) Refused (7)
	104 - During the past 12 months/since birth, did you have any difficulties or delays getting services for child b/c they were not eligible for the services? (interview); C*4Q03_A*	No (0) Yes (1) Don’t know (6) Refused (7)
	239 - Child did not get all of the mental health care or counseling they needed b/c no insurance (interview); *C4Q05_6BR02*	Cost was too much (1) **No insurance (2)** Health Plan Problem (3) Can’t find provider who accepts child’s insurance (4) Not avail. in area/transport problems (5)

		Not convenient times/could not get appointment (6) Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9) Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don’t know (77) Refused (99)
	238 - child did not get all of the mental health care or counseling they needed b/c can't find provider who accepts child’s insurance. (interview); *C4Q05_6BR04*	Cost was too much (1) No insurance (2) Health Plan Problem (3) **Can’t find provider who accepts child’s insurance (4)** Not avail. in area/transport problems (5) Not convenient times/could not get appointment (6) Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9) Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don’t know (77) Refused (99)
	334 - family did not get all of the mental health care or counseling that was needed b/c no insurance. (interview); C*4Q06_3BR02*	Cost was too much (1) **No insurance (2)** Health Plan Problem (3) Can’t find provider who accepts child’s insurance (4) Not avail. in area/transport problems (5) Not convenient times/could not get appointment (6) Provider did not know how to treat or provide care (7) Dissatisfaction w/ provider (8) Did not know where to go for treatment (9)

		Child refused to go (10) Treatment is ongoing (11) No referral (13) Lack of resources at school (14) Did not go/neglected/forgot appt. (15) Other (16) Don't know (77) Refused (99)
	406 - Type of insurance coverage at interview (interview); *TYPEINS/C7Q10*	Medicaid (1) Medicare (2) SCHIP (3) Medigap (4) Military (5) Indian health Service (6) private insurance (7) single service plan (8) other (9) don't know (77) refused (99)
	418 - Past 12 months, child ever not insured (interview); *UNINS_YR/C7Q11*	No (0) Yes (1) Don't know (6) Refused (7)
	419 - Past 12 months, # of months w/o coverage (interview); *MS_UNINS/C7Q12*	N Months (N) Don't know (96) Refused (97)

Appendix D

Due to the length of the original survey instrument used in the 2009-2010 NS-CSHCN it has not been included in full here, however it is publicly available at the following website: https://www.cdc.gov/nchs/data/slaits/NS_CSHCN_Questionnaire_09_10.pdf.

Appendix E

Variable Recoding and Construction of Key Variables

Original Interview Data Variable	**Original Response Set**	**Recode Needed**	**Current Study Variable**	**Transformed Values**
C9Q03R	0 = 0 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = 8 9 = 9 10 = 10 11 = 11-20 12 = 21+ 996 = don't know 997 = refused	If response C9Q03R + response C9Q04R <10, then new variable Time Burden = 0 If response C9Q03R + response C9Q04R ≥10, then new variable Time Burden = 1 If C9Q03R = 996 or 997 or if C9Q04R = 996 or 997, then new variable Time Burden = 999	Time Burden (TBD)	1 = yes 0 = no 999 = missing
C9Q04R	0 = 0 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = 8 9 = 9 10 = 10 11 = 11-20 12 = 21+ 996 = don't know 997 = refused			
C9Q05	1 = yes 0 = no 6 = don't know 7 = refused	1 = 1 0 = 0 6, 7 = 999	Financial Burden (FBD)	1 = yes 0 = no 999 = missing
C9Q10	1 = yes 0 = no 6 = don't know 7 = refused	If C9Q10 = 1 or C9Q11 = 1 or C9Q06 = 1, then new variable Employment Burden = 1	Employment Burden (EBD)	1 = yes 0 = no 999 = missing

C9Q11	1 = yes 0 = no 6 = don’t know 7 = refused	If C9Q10 = 0 and C9Q11 = 0 and C9Q06 = 0, then new variable Employment Burden = 0 If C9Q10 = 6 or 7 or C9Q11 = 6 or 7 of C9Q06 = 6 or 7, then new variable Employment Burden = 999		
C9Q06	1 = yes 0 = no 6 = don’t know 7 = refused			
RELATIONR	1 = mother (biological, step, foster, adoptive), 2 = father (biological, step, foster, adoptive), 3 = other relative, 6 = Don’t know, 7 = Refused	1 = 1 2 = 2 3, 6, 7 = 999	Caregiver Gender (CG)	1 = female 2 = male 999 = missing
race4_09	1 = Hispanic/Latino 2 = White 3 = Black 4 = Other 6 = Don’t know 7 = Refused	1 = 1 2 = 2 3 = 3 4 = 4 6, 7 = 999	Race/Ethnicity (RE)	1 = Hispanic/Latino 2 = White 3 = Black 4 = Other 999 = missing
educ_09	1 = < 8th grade 2 = 9-10th grade 3 = HS grad/GED 4 = vocational/trade 5 = some college 6 = Associate’s 7 = Bachelor’s 8 = Master’s 9 = Doctorate 96 = don’t know 97 = refused	1, 2 = 1 3 = 2 4, 5, 6, 7, 8, 9 = 3 96, 97 = 999	Household Parent’s Education Level (PEL)	1 = less than HS 2 = HS graduate 3 = above HS education 999 = missing
NM_SPR	# CSHCN entered	1 = 1 1-100 = 2	Family Size (FS)	1 = 1 CSHCN 2 = 2+ CSHCN
C3Q26	1 = a lot of difficulty 2 = a little difficulty 3 = no difficulty 6 = don’t know 7 = refused	1 = 1 2 = 2 3 = 3 6, 7, = 999	Child’s Chronic Physical Pain Level (CPL)	1 = high 2 = low 3 = none 999 = missing

C3Q33	1 = a lot of difficulty 2 = a little difficulty 3 = no difficulty 6 = don't know 7 = refused	1 = 1 2 = 2 3 = 3 6, 7, = 999	Child's Behavior Problem Level (BPL)	1 = high 2 = low 3 = none 999 = missing
C3Q32	1 = a lot of difficulty 2 = a little difficulty 3 = no difficulty 6 = don't know 7 = refused	1 = 1 2 = 2 3 = 3 6, 7, = 999	Child's Anxiety/Depression Level (ADL)	1 = high 2 = low 3 = none 999 = missing