Socioeconomic Status, Family Functioning and Delayed Care Among Children With Special Needs

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Abstract

Parents of children with special healthcare needs (CSHCN) face tremendous stress in caring for their children. Families of CSHCN face increased barriers to health services as evidence also reflects the influence of socioeconomic factors on access. This study investigates the impact of socioeconomic factors and family functioning on delayed care. Descriptive, bivariate, and adjusted multivariate logistic regression were performed using sampling weights. Our findings suggest that family dynamics are more impactful on delayed care than socioeconomic predictors. Promoting family-centered care that incorporates social support for families to reduce barriers is essential for improved quality of life and health outcomes.

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Introduction

An estimated 11.2 million children under the age of 18 in the US have special health care needs, representing about 23 percent of U.S. households with children that have at least one child with special health care needs (Caicedo, 2014; U.S. Department of Health and Human Services - Health Resources and Services Administration - Maternal and Child Health Bureau, 2013). The Bureau of Maternal and Child Health defines special healthcare needs (CSHCN) as; 1) a child who has a compendium of "chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type, or 2) amount of health and related services beyond that required by children generally" (Benevides, Carretta, & Mandell, 2016; Burns et al., 2010; Kuhlthau, Kahn, Hill, Gnanasekaran, & Ettner, 2010; D. Z. Kuo & Houtrow, 2016; Pollard et al., 2014). Children with special needs have long been designated a priority population for health care policy (D. Z. Kuo & Houtrow, 2016; McPherson et al., 1998; US Department of Health and Human Services, 1987), yet disparities in care remain. Health outcomes increasingly become more favorable for CSHCN in recent years, which in turn translates to population growth for adults with special health care needs in the long term (Okumura, Hersh, Hilton, & Lotstein, 2013).

Children with special health needs require special and constant access to medical services so that the child can develop into an otherwise healthy adult and maintain a quality of life with dignity. The range of health and medical services include therapies, home healthcare, prescription drugs, mental healthcare, medical equipment, and dental services (Rosen-Reynoso et al., 2016). Many children with special needs, healthcare services are either partially covered or not covered by insurance plans. This leaves many families to fund the remaining portion of healthcare costs. In additionally, most of the families have household incomes fall below the

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federal poverty line. In particular, parents of children with activity limitations or special healthcare needs have lower employment and increased work absences than other parents (Kuhlthau et al., 2010). Furthermore, families of CSHCN experience greater financial stress than families of children without CSHCN (Goudie, Narcisse, Hall, & Kuo, 2014). Additionally, families of children with chronic conditions experience more out-of-pocket costs than families of unaffected children (Kuhlthau et al., 2010; Resch et al., 2010). On average, approximately 22% of families with children with special needs spend more than $1,000 out-of-pocket on healthcare services with another 12% of CSHCN families spending between $501 and $1000 on healthcare services annually (U.S. Department of Health and Human Services - Health Resources and Services Administration - Maternal and Child Health Bureau, 2013). As a result, parents of children with special healthcare needs are more likely to report unmet healthcare needs than parents of children without these healthcare needs, particularly if the child is affected by two or more conditions (Schieve et al., 2012). Consequently, "children and youth with special health care needs and their families often need services from multiple systems – health care, public health, education, mental health, and social services" (Health Resources and Services Administration, 2016).

Caring for children with special health care needs requires more effort and resources, to overcome barriers to care than caring for children without these conditions, which can make coping with their diagnosis emotionally draining (Ammari, Morris, & Schoenebeck, 2014). In August 2016, the US Social Security Administration and Institute of Medicine requested that the National Academies of Sciences, Engineering, and Medicine convene an ad hoc committee to study health outcomes among school-aged children with disabilities (National Academy of Sciences, 2017). In particular, the committee was charged with examining the congruency of

programs, services, and support systems available to children with disabilities children and their families. Further, the Committee has a broad scope which includes; examining utilization rates for existing services and health programs. At the time of our study, the Committee has yet to issue its report. The study reported on here therefore is in line with the overarching goals and vision of the Maternal Child Health Bureau (MCH) at the Health Resources and Services Administration (HRSA), which aims for optimal health and quality of life for all children and youth with special health needs and their families.

Numerous studies have identified family relationship dynamics and functioning and parental coping mechanisms for dealing with the stresses of a child's health condition as potent predictors of the child's wellness and adaptation to the chronic health conditions (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010; Geist, Grdisa, & Otley, 2003). Evidence from some of these studies suggest that parents of CSHCN typically report higher rates of stress compared to parents of children without special health needs (Estes et al., 2013; Hayes & Watson, 2013; Neece, Green, & Baker, 2012). Additionally, some of these parental stressors among children with special healthcare needs have greater negative effects on the quality of child care than variables such as income, time available for a child, and social support when trying to predict parenting stress, better than the child's functional abilities (Ammari et al., 2014). Higher levels of stress have been reported among parents of younger children with special healthcare needs (Neece et al., 2012; Sipal, Schuengel, Voorman, Van Eck, & Becher, 2010). Neece (2012) concluded that there is a transactional relationship between parental stress and child behavior problems. Caring for a child with behavioral problems exerts increased stress on parent, which can complicate the parent's ability to care for the child, including facilitating access to health care services. When the child has a parent or caregiver who is chronically stressed, it complicates

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parental ability to appropriately cater to the needs of the child especially one with disabilities which further exacerbates the child's behavioral problems (Neece, 2014; Neece et al., 2012).

Conceptual framework

This study draws from Falkov's integrated systemic Family Model (Falkov, 2012) which illustrates how a child's mental health and development needs affect the adult or parents' parenting, adult mental health, and family relationships by aggravating their mental health illness and acting as stressors and reducing their protective ability and resilience. The parent or caregiver's mental health status affects their parenting or caregiving capacity and family relationship dynamics and functioning, which in turn influences the child's mental health and healthy development. Both the needs of the child and those of parents, therefore, have implications for socio-economic resources and support services which are at the disposal for both, children and their parents as well as cultural and community influences. The Family Model also acknowledges that the links between mental health and parenting thus begin early in life, are evident across the lifespan, and are an important determinant of health and social outcomes in succeeding generations (Falkov, 2012). As illustrated, the systemic Family Model demonstrates the key areas of focus and associated interactions using six Domains and ten (10) bidirectional arrows as follows:

Domain 1: Adult/parental mental illness

Domain 2: Child mental health and development

Domain 3: Family relationships (parenting & marital interactions)

Domain 4: Risk & protective factors

Domain 5: Services for children & adults

Domain 6: Cultural & community influences

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In short, Falkov's conceptual model, which is described was adopted in this study to facilitate scaffolding and understanding of the issues under investigation, while delineating clear parameters and boundaries for the entire study (Creswell, 2009; Miles & Huberman, 1994; Miles, Huberman, & Saldaña, 2013).

Hypotheses

Previous studies have focused solely on the effect of socioeconomic factors on access to care for CSHCN. In addition to socioeconomic factors that influence access to care, we examine and compare characteristics of CSHCN and their family dynamics with delayed health care. In order to answer the research question, we posed three hypotheses as follows:

1. Children with special health care needs are more likely to experience delayed medical care than other children;
2. Children from families in the higher socioeconomic classes will be less affected by delayed care; and
3. Family functioning will have a significant effect on delayed health care among children with special healthcare needs.

Methods

Design and Study Population

This research study utilizes data from the 2011-2012 National Survey of Children's Health (NSCH), funded by the U.S. Department of Health and Human Services, Maternal and Child Health Bureau. The NSCH provides cross-sectional data on multiple, intersecting aspects of children's lives—including physical and mental health, access to quality healthcare, and the child's family, neighborhood, school, and social context (Data Resource Center for Child and Adolescent Health, n.d.). Data collection were conducted through random selection of United

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States telephone numbers which are further screened to identify households with one or more children under the age of 18 (Silverberg, Joks, & Durkin, 2014). Surveys were conducted by the National Center for Health Statistics at the Centers for Disease Control, with interviews in English, Spanish, Korean, Mandarin, Cantonese, and Vietnamese (Silverberg et al., 2014).

Dependent Variable

The outcome variable for our study is, "delayed use of healthcare services by children with special needs." Parents of the children with special health care needs were asked, *"During the past 12 months, was there any time when [CHILD's NAME] needed health care but it was delayed or not received?"* A *'yes'* response was considered delayed healthcare and coded as '1' while a 'no' response was coded '0" signifying met needs.

Independent Variables

The independent variables comprised of the socio-demographic variables including age, sex, race/ethnicity, parental employment, insurance, and Medicaid or SCHIP coverage. Need variables included having a doctor recommendation for treatment or counseling, a doctor recommendation for the child to see a specialist, an index child having behavioral problems, the child needed mental health services, autism, developmental delay and intellectual delay), socioeconomic variables. Parental characteristics included: parental frustration, positively coping with the demands of caring for a child with specials needs, problems paying medical bills, and parental social support. Specifically, parental social support was defined as having someone to whom the parent or caregiver can turn to for day-to-day emotional with fulfilling the responsibilities of parenthood or raising a child with special needs. The familial variable was coded as '*1*' if a support system existed and '0' otherwise.

Data Analysis Methods

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We computed descriptive, frequencies for categorical variables and mean (SD) and bivariate proportions for the covariates and outcome variables respectively. Data were weighted to account for the complex sampling design and weighting procedures. Stata software packaged version 14 for Windows, (Stata Corp Inc., College Station, TX) was used for all the analysis, with an alpha of 0.05 for significance level. We computed frequencies and percentages for categorical variables (see Table 1). We performed a Chi-square test to find the association and significance between each covariate and delayed care for characteristics of CSHCN, socioeconomic factors, and family dynamics (see Tables 2, 3, and 4). Tables 2, 3, and 4 also include bivariate regression analyses to estimate the odds of each covariate and delated care. Finally, we computed multivariate logistic regressions to estimate the adjusted odds of delayed care while adjusting for cofounders (Tables 2, 3, and 4).

Results

The results of our study are presented in three sections addressing, descriptive, bivariate and multivariate results. Tables 1 contains the univariate weighted proportions of the covariates, while Tables 2, 3, and 4 breakdowns the results of the bivariate and multivariate analysis by sociodemographic, health care utilization and need domains.

Descriptive

The sample means age was 10.98 (SD =4.39) years of age; 37.2% were female and 62.8% were male. The majority of the sample was White (67.6%), 15.6% Black, and 16.8% were other minorities (Table 1 below). A significant proportion of the children in the study had health insurance coverage (96.3%), 90.3% had a regular doctor, and 93.3% saw a doctor in the 12-month period preceding the interview. It is important to note that 52.3% of the sample had Medicaid or State Children's Health Insurance Program (SCHIP) for insurance coverage. Our

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study shows that the proportion of our sample that needed treatment or counseling was 34.4% and 28.5% had a parent who self-reported a behavior problem. Unfortunately, there were 48.6% who did not see a mental health care professional during the period preceding the interview despite having behavior problems or needing treatment or counseling. At the state level, Medicaid and SCHIP funding for mental health care services are limited (Behrens, Lear, & Price, 2013). These differences in coverage and utilization of services suggest a gap or lack of mental health services for children receiving government-funded health insurance. The differences may be a result of state Medicaid programs that have separate contracts for behavioral health services; leading to fewer mental health care providers (Chiri & Warfield, 2012).

[Insert Table 1 here]

Characteristics of CSHCN and Delayed Care

Bivariate analysis.

Weighted results of the bivariate and multivariate analyses are presented in Table 2 for characteristics of CSHCN and delayed care. Overall, there were significant differences in CSHCN (16.5%) who experienced delayed health care than children without special needs (1.9%). Similarly, higher proportions of children with special needs who saw a mental health care professional experienced a delay in care than those who did not (7.3%). We found there was were significantly lower differences for children who needed treatment/counseling (8.5%), had behavior problems (6.3%), and a doctor said the child needed to see a specialist (4%) with delayed care ($\chi^2 = 20.9$; $p < 0.001$, $\chi^2 = 6.68$; $p < 0.01$, and $\chi^2 = 41.3$; $p < 0.001$ respectively). No statistically significant differences were found among CSHCN who had either autism, developmental or intellectual delays.

[Insert Table 2]

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Socioeconomic Factors and Delayed Care

Bivariate analysis.

Results also suggest higher proportions of delayed care for our sample with each socioeconomic factor defined (see Table 2). These differences in proportion were only statistically significant for parent's employment status and having health insurance in the 12-month period preceding the interview ($\chi^2 = 45.0$; $p < 0.001$ and $\chi^2 = 12.7$; $p < 0.001$) respectively.

[Insert Table 3]

Family Functioning and Delayed Care

Consistently research has shown that family functioning has a significant impact on the health and quality of life of children with special needs. All were statistically significant in the bivariate analysis (see Table 2). Each predictor suggested higher proportions with the expectation of the family having problems paying medical bills, which results showed similar proportions between families who did (8.8%) and did not (8.9%) have problems paying ($\chi^2 = 82.1$; $p < 0.001$).

Multivariate analysis.

At the multivariate level, several factors were significantly associated with delayed care in children with special needs at the adjusted level predictor suggested a higher likelihood of delayed care with the expectation of children with behavioral problems. In general, CSCHN were statistically two times more likely (AOR = 2.00; CI: 95% 1.10 – 3.61) to have delayed care than children without special health care needs. Children with special healthcare needs and a diagnosis of autism experienced delayed care more often (57%) CSHCN who did not have autism (AOR = 1.57; CI: 95% 1.06-2.32). CSHCN who received treatment or counseling in the 12-month period preceding the interview were significantly more likely to have had delayed care (AOR = 1.81; CI: 95% 1.08 – 3.04). Ironically, CSHCN who had a recommendation to see a

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specialist were three times (AOR = 3.09; CI: 95% 2.03 – 4.71) to experience a delay in care than CSHCN who were not recommended.

Results of the multivariate analysis suggest that children whose parents report frustration are significantly more likely to have delayed care (AOR = 7.68; 95% CI: 5.06-11.6. Additionally, children whose parents report difficulty paying bills also experience significant delays in critical healthcare services (AOR = 2.17; 95% CI: 1.52-3.09). Children with special needs whose parents self-reported positively coping with parenthood were 14% less likely experienced delayed care in the 12-month period preceding the (AOR = 0.86; 95% CI: 0.48-1.53). For parents who had social support, lower odds of delayed care were observed, but results were only significant at the bivariate level.

[Insert table 4].

At the multivariate level, those with insurance were 66% less likely to have had delayed care (AOR = 0.34; CI: 95% 0.15-0.73). Medicaid or SCHIP recipients were nearly two times more likely to experience delayed care (AOR = 1.96; CI: 95% 1.32-2.92). Having a regular doctor and seeing a doctor also led to higher chances of delayed access and use of healthcare services. However, these differences were not statistically significant.

Discussion

The aim of this study was to examine the impact of characteristics of CSHCN, socioeconomic factors, and family dynamics on delayed care for CSHCN. Expanding on the knowledge from previous studies, we hypothesized that the impact of delayed care would be higher for CSHCN, socioeconomic factors would decrease delayed care for families with favorable statuses, and that family dynamics would have similar effects on delayed care for CSHCN as the relationship between socioeconomic factors and access to care. Our first

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hypothesis was proven true, as higher proportions and odds of delayed care were observed. As expected, socioeconomic factors suggested very traditional implications for delayed care. For example, parents who worked or parents of children with health insurance were less likely to experience delayed care. One explanation for this difference could be that their parents can afford private insurance to supplement care that is not covered by government-funded health care, thus decreasing the chance of delayed care (Krauss, Gulley, Sciegaj, & Wells, 1993).

Based on previous research as well as the results of the current study, our first hypothesis that CSHCN would have more delays in medical care due to their diagnosis than children without special health care needs was validated. This is also consistent with the conceptual framework of this study in that the evidence suggests that having CSHCN impacts on the parents' ability to respond to their health needs by acting as stressors and reducing parents' resilience and protective ability. From these finding, we can infer that the mental health of adults with childcare responsibilities are affected by CSCHN and therefore should be acknowledged as a global public health issue requiring a greater focus on individuals within their family context.

Key findings of our study suggest that delayed care was still a persistent issue for CSCHN although in recent years there has been an increase to resolve challenges and barriers to care for people with disabilities. Additionally, we found that the proportions of diagnosis (autism, developmental delays, or intellectual delays) varied at the bivariate level, but the likelihood of having delayed care was higher for children who had autism or an intellectual delay about both the bivariate and multivariate levels. However, the three diagnosis-related predictors were not found to be statistically significant except autism at the multivariate level. This could reflect stigmas associated with autism and should be researched further.

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Surprisingly, CSHCN who had a doctor say they needed to see a specialist were over three times as likely to have had delayed care at both the bivariate and multivariate levels. Often is it easier to access a specialist with a referral from a primary care physician (Dunlea & Lenert, 2015; van Dijk, Korevaar, Koopmans, de Jong, & de Bakker, 2014) and many insurance plans require one. This finding may suggest that there is a strong disconnect for CSHCN with referrals to specialty care. It also circles back to echo known barriers of access to care that were previously mentioned. To be clear on this issue, we suggest that future research should show if this is a direct effect of time between referrals from doctors to specialist or if it is lack of specialty care professionals for people with disabilities. Another reason there for a delay in care after a referral is that adding more professionals to a care plan can make decisions about treatment options more difficult for parents (Stille et al., 2013). Also, for those who were able to see a mental health care professional in the selected timeframe, the likelihood to experience to have delayed care was 69% less likely, leaving more than a quarter (31%) of the sample with the likelihood of delayed care. While these children eventually did see a mental health care professional, there was still a great chance that they were not able to see them in a timely manner.

Socioeconomic Factors

Evidence from this study suggest that adverse socio-economic factors can be stressors which lead to delayed access to care for parents and families with CSHCN, even though this is to a lesser extent compared to the influence of social support, family relationship dynamics and functioning. Ironically, children who had health care coverage in the 12-month period preceding the interview were 66% less likely to have delayed care than those children without special healthcare needs with no coverage. However, for those who specified being enrolled in Medicaid

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or SCHIP only, results suggest lower rates of delayed care. CSHCN who were enrolled in Medicaid or SCHIP were twice as likely to experience delayed care compared to children without special needs who were enrolled. Szilagyi (2012) cited provider reimbursement for government-funded insurance tended to be lower than private insurer reimbursement; making some providers reluctant to care for the publicly insured, particularly children who have public insurance and are at high-risk.

Other socio-economic factors that contribute to delayed care among children with special needs include; out-of-pocket cost, provider lack of knowledge and experience in providing care for disabled children, inadequate equipment, and discrimination (Ali et al., 2013; Krahn, Walker, & Correa-De-Araujo, 2015). These findings are consistent with the conceptual framework for this study which acknowledges that complex health needs for children have implications for resources and support services which are affected by external factors, such as cultural, community or socio-economic ones.

Understanding the role of these factors and the potential negative effect they have on the ability of CSHCN's ability to access critical care services is important for public health social workers. Resolving these issues is important because most CSHCN will rely on publicly-funded health care into adulthood (Okumura et al., 2013)and people with disabilities are entitled to the same health equity and opportunities as people without disabilities.

Results from this study suggest that family functioning had a greater influence on delayed care than socioeconomic predictors. Parents of CSHCN experience significant stress and frustration as demonstrated in our findings and previous studies. Falkov's Family Model alludes to the effect family stress arising out of health issues for either or both children and parents having the potential to negatively impact on family relationships and functioning (Falkov, 2012).

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Evidence from this study shows that parents who coped positively with raising CSHCN were less likely to have delayed care for their children. Coping is a proactive, practice that encompasses a combination of behavioral, emotional, and cognitive attempts to help manage the distress brought on by the stressor (Zaidman-Zait et al., 2017). Traditionally and culturally, mothers are the primary caregivers of their children (Neves et al., 2013; Pridham, Limbo, & Schroeder, 1998). Woodman (2013) set out to assess the role of coping strategies for depressive symptoms and parenting efficacy outside of socioeconomic factors, characteristics of their children, and adolescent behavioral problems for mothers with adolescents with developmental disabilities. Similar to this current study, the results suggested socioeconomic status did not produce a significant change in maternal depressive symptoms or parenting efficacy (Woodman & Hauser-Cram, 2013). Finally, after longitudinal analysis of both problem-focused and emotion-focused coping strategies, Woodman (2013) concluded that coping indeed plays a role in maternal well-being over time. Consistent with findings from Woodman parenting and family functioning, are significantly associated with lower odds of delayed care is decreased when family functioning when parents of CSHCN have positive experiences with coping.

Social support, family relationship dynamics and functioning and delayed care

Family structure, including social support and social network, has been shown to mediate the burden experienced by families with special needs (DeHoff, Staten, Rodgers, & Denne, 2016). The evidence presented from this study on positively coping, in conjunction with findings for parental social support, suggests that having positive family relationships and social support contribute to fewer instances of delays in care for CSHCN. Evidence from this study, as with previous studies shows that parents of CSHCN self-reported high levels of frustration or stress (Kissel & Nelson, 2016; Neece, 2014). Social support has been linked to not only effective

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coping behaviors, but other positive health statuses such as a sense of stability, psychological well-being, and perceived control among others for parents of CSHCN (Langford, Bowsher, Maloney, & Lillis, 1997; Peer & Hillman, 2014). Furthermore, social support has also been defined as an interpersonal transaction between emotional and instrumental dimensions (Norona & Baker, 2014) that is one of the best coping mechanisms for parents of CSHCN (Findler, Klein Jacoby, & Gabis, 2016; Zaidman-Zait et al., 2017).

When parents do not have any means of social support, stressful situations may impact susceptibility to increased psychological distress, emotional and functional problems, and illnesses (Findler et al., 2016). Parenting CSHCN can also have a negative effect on other family relationship dynamics such as finding appropriate and affordable child care, making work decisions, obtaining education/training, having additional children, problem-solving, and relying on government-funded insurance (Reichman, Corman, & Noonan, 2008; Zaidman-Zait et al., 2017).

As mentioned previously, parents of children with special needs often face more financial burdens associated with child care than parents of children without special needs. Evidence from this study shows that parents self-reported that when they had problems paying medical bills, they were over 4 times more likely to have delayed care at the bivariate level and over two times more likely at the multivariate level (AOR = 4.11; 95% CI: 2.99 -5.66, $p < 0.001$). Possible explanations of this finding could stem from parents having to make their children skip or postpone appointments for reasons such as disagreement with new treatment plans, the consequences associated with treatment, a belief that the benefits do not outweigh the cost, not retrieving prescribed medication in a timely manner, or avoiding additional medical costs due to lack of funds (Cameron et al., 2014). Although many CSHCN are covered by government-

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funded programs that reimburse providers a significant portion of the costs, there are still considerable amount of out-of-pocket expenses that are not covered (Barrett et al., 2015). The out-of-pocket costs leave many families with limited means for providing needed care to their children.

Social support, relationship dynamics and functioning can be instrumental in terms of health care when parents are supported with various healthcare-related activities such as investing in time to make their child's appointment on time, finding doctors who are capable of care for CSHCN, assisting with transportation, or helping understand and adjust to new treatment plans (Caicedo, 2014). Children whose parents or caregivers have social support are less likely to experience delays in health care (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2017; Van Cleave, 2015). Parents with social support gain understanding and develop the ability to care for and be advocates for their children (DeHoff et al., 2016). Social support, along with positive family relationship dynamics, are critical because they assist parents in maintaining functioning and stability for their family and balance in their own lives (Peer & Hillman, 2014).

Parallels can therefore be drawn between the findings of this study and Falkov's model in that, in both, the child's mental health and special health care needs, there is a transactional relationship between parental stress and child health and behavioral difficulties (Domain 1 and 2). As with this study, Falkov (2012) argued that the family relationship dynamics and functioning are influenced by the stress of a child's health condition and parental stress (Domain 3). As evidence from this study suggests, difficult family relationship dynamics and functioning have significant implications for delaying access to health care for CSHCN and behavior difficulties. These difficulties which are associated with their broader special health care needs or mental health issues could lead to increased parental stress, difficult family relationship

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dynamics, and potentially adult mental health, which, as evidence from this study shows, further exacerbates the development of the child's behavior problems due to delayed access medical care for CSHCN. In both instances, this complicates parental ability to appropriately access health care timely and meet needs of the children who have either special health care needs or mental health needs. As with the Falkov's conceptual framework, therefore there are implications for support services for both children and adults, resilience, protective factors, and resources (Domain 4), for this study too, that determine the timely access to health services for both children and adults (Domain 5). The influence of culture and community services (Domain 6) in the Falkov's conceptual framework can be likened to external factors such as the impact of the family's culture and socio-economic influences on CSHCN access to services, which this study also set out to investigate. Based on findings and the links made with Falkov's Family Model a conceptual model for this study in relation to the transactional relationships between multilevel influences to access to health services for CSHCN can be presented in Figure 1. [Insert Figure 1: A Family-Centered Model for delayed care for children with special health needs]

Although similar in many respects, what makes the proposed Family-Centered Model for delayed care for children with special health care needs different from the Falkov's family model is that more specifically, this model is about children with special health needs and mental health needs. In line with the findings of the study, the proposed model emphasizes the centrality of family relationship dynamics and functioning, social support and socio-economic factors in influencing children's special health care needs and the special support needs for the caregivers concerning access to support services. While the social support and other resources can act as a protective factor and a source of resilience, adverse economic factors on the other hands can act

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as stressors that heighten risks for both caregivers and children with special health care needs. Yet, in line with Falkov's family model, the proposed Family-Centered Model, as evidence from this study suggests, both specialized services for children with special health care needs and specialized support services for parents and caregivers would be in turn be influenced by external factors such as the cultural parenting practices and available community resources. This is consistent with assertions made earlier with regards to a large body of literature that shows that culturally mothers are the primary caregivers of their children (Neves et al., 2013; Pridham et al., 1998). As discussed in the section below, a number of implications for practice for delayed care for children with special health care needs can therefore be drawn from the findings of this study.

Implications for Practice, Policy, and Research.

Children with special health needs are particularly vulnerable to complex medical problems. These problems can be compounded by the lack coherence in family, community and health systems resources and infrastructure. We recommend that healthcare providers and social workers include features of social support into care coordination for CSHCN. Based on our results, it would be beneficial for healthcare providers and social workers work together to incorporate family-centered care programs by promoting family advisory boards and family/peer support groups, family presentations on care experiences, and hiring family members as consulting staff to specific programs (Dennis Z. Kuo et al., 2012). Because social workers are very knowledgeable on how to interact with many types of families (Ferguson, 2016), it would be ideal for them to expand on their roles with implementing care coordination and family-centered care plans (Algood, Harris, & Sung Hong, 2013). These types of programs are ideal for families that do not have support from biological family members, and those who may be the first in their family history to seek care for CSHCN. Some hospitals have proven to be successful

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by incorporating family-centered care programs and encourage family leaders to participate in family advisory boards or peer support groups (Dennis Z. Kuo et al., 2012). Utilizing social workers and other mental health clinicians beyond the diagnosis period can provide therapeutic opportunities to facilitate stress management and provide support for parents as they navigate complex medical systems and limited resources. Additionally, this study supports the finding of reimbursement discrepancies between government and private health insurers. We would encourage legislative officials, lobbyists, and advocacy groups to push for financial parity regarding mental health reimbursements to ensure children receive quality care that may be vital to their developmental well-being. Additional legislative action should be focused on increasing resources for children and families with special health care needs. Further, coordination of resources for families and children with special health needs would also alleviate some of the burdens and ease the transition into needed care. Furthermore, continued research should examine the long-term effects of programs that include family social support as it relates to the occurrence of care delays.

Limitations of the study.

First, NSCH is dependent upon the parents' ability to report a diagnosis of their children rather than using medical records (Chiri & Warfield, 2012). Although parent report has been shown to be a reliable measure of healthcare quality, there was no way to verify the information (Chiri & Warfield, 2012; Zuckerman, Lindly, Bethell, & Kuhlthau, 2014). Second, the NSCH does not have any measures to account for the severity of the children's diagnosis, which can lead to misleading results especially for children on the autism spectrum. Third, the survey only reaches households with landline telephones, which decreases the number of participants. Finally, our study uses specific data for intellectual delays, developmental delays, and autism,

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but lumps all other special care needs such as cerebral palsy and schizophrenia. Despite these limitations, this study still gives important insight on the impact of characteristics of CSCHN, risks and stressors from socio-economic factors, social support as a protective and resilience factor and a resource, and family dynamics in relations to delayed care for children with special needs.

Conclusion

This study contributes to our understanding of the difference in socioeconomic factors and family dynamics on delayed care for CSHCN. Collectively, our findings provide evidence to parental social support positively influencing the outcome of delayed care. Having delays in can add to the frustration and stress of parenting CSHCN. Experiences with parental social support appear to be important constructs for coping with common life stressors of parents with CSHCN. We conclude that family relationship dynamics have a greater impact on delayed care than socioeconomic factors. A more family-centered approach that ensures that parents have social support and can cope with caring for their children in turn decrease delays in care is required. The use of qualified mental health professionals who understand the systemic interplay of factors described in the proposed family-centered model' can positively affect family support reducing the presence of care delays.

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Table 1: Descriptive Statistics of Children with Special Healthcare Needs		
	Sample characteristics	
Independent variables	*Count (n=5503)*	*Weighted (%) (n=5503)*
Age (mean =*10.98; sd =4.39*)		
<11	2752	52.8
>12	2751	47.2
Gender		
Male	3477	62.8
Female	2026	37.2
Race/Ethnicity		
White (ref)	4020	67.6
Black/African-American	559	15.6
Other minorities	924	16.8
Employment Status		
Not employed (ref)	1205	23.7
Employed	4298	76.3
Insurance		
Yes	5352	96.3
No (ref)	151	3.7
Have a regular doctor		
Yes	5149	90.3
No (ref)	354	9.7
Medicaid or SCHIP		
Yes	2754	52.3
No (ref)	2599	47.7
Delayed care		
Yes	949	17.7
No (ref)	4554	82.3
Doctor said child needed a specialist		
Yes	596	10.2
No (ref)	5007	89.8
Has the child seen a doctor		
Yes	5190	93.3
No (ref)	313	6.7
Mental health professional or services used		
Yes	2802	51.4
No (ref)	2701	48.6

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Child with special health care need		
Yes	4855	86.7
No (ref)	648	13.3
Child needs treatment or counseling		
Yes	1779	34.3
No (ref)	3724	65.7
Does the child have a behavior problem		
Yes	1301	28.5
No (ref)	4202	71.5
Does the child have autism		
Yes	1623	28.7
No (ref)	3880	71.3
Developmental delay		
Yes	3111	56.8
No (ref)	2392	43.2
Intellectual delay		
Yes	933	15.2
No (ref)	4570	84.8
Positive parental coping with parenthood		
Yes	5193	92.8
No (ref)	310	7.2
Family problems paying bills		
Yes	1241	24.9
No (ref)	4262	75.1
Parental social support		
Yes	762	16.5
No (ref)	4741	83.5
Frustration		
Yes	2458	44.7
No (ref)	3045	55.3

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Table 2: Characteristics of CSHCN and Delayed Care

	Bivariate Analysis				*Multivariate Analysis*	
Independent variables	*Weight (Yes %)*	χ^2	*OR*	*95% CI*	*OR*	*95% CI*
Child with special health care need		11.8***				
Yes	16.5		2.40***	1.44-4.02	2.00*	1.10-3.61
No (ref)	1.9		1.00	--	--	--
Child needs treatment or counseling		20.9***				
Yes	8.5		2.00***	1.48-2.70	1.81*	1.08-3.04
No (ref)	9.2		1.00	--	--	--
Doctor said child needed a specialist		41.3***				
Yes	4.0		3.65***	2.41-5.54	3.09***	2.03-4.71
No (ref)	13.7		1.00	--	--	--
Does the child have a behavior problem		6.68**				
Yes	6.3		1.51**	1.10-2.06	0.84	0.56-1.25
No (ref)	11.4		1.00	--	--	--
Mental health professional or services used		6.09*				
Yes	10.4		0.69**	0.51-0.93	1.09	0.76-1.55
No (ref)	7.3		1.00	--	--	--
Does the child have autism		2.16				
Yes	5.8		1.27	0.92-1.75	1.57*	1.06-2.32
No (ref)	11.9		1.00	--	--	--
Developmental delay		1.63				
Yes	9.4		0.83	0.61-1.11	1.01	0.59-1.74
No (ref)	8.4		1.00	--	--	--
Intellectual delay		0.34				
Yes	2.9		1.12	0.75-1.68	1.07	0.59-1.25
No (ref)	14.8		1.00	--	--	--

Note: All percentages are weighted proportions; Significance levels: * p<0.05, ** p<0.01 and ***p<0.001

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Table 3: Family Socioeconomic factors on Delayed for CSHCN

	Bivariate Analysis				*Multivariate Analysis*	
Independent variables	*Weighted (Yes %)*	χ^2	*OR*	*95% CI*	*OR*	*95% CI*
Employment Status						
Yes	12.0	45.0***	0.60**	0.43-0.83	0.71	0.46-1.05
No (ref)	5.7		1.00	--	--	--
Insurance		12.7***				
Yes	16.2		0.29***	0.14-0.60	0.34**	0.15-0.73
No (ref)	1.5		1.00	--	--	--
Medicaid or SCHIP		3.11				
Yes	10.2		1.30	0.97-1.74	1.96***	1.32-2.92
No (ref)	7.5		1.00	--	--	--
Have a regular doctor		0.06				
Yes	15.9		0.94	0.58-.1.54	1.70	0.98-2.93
No (ref)	1.8		1.00	--	--	--
Has the child seen a doctor		0.84				
Yes	16.8		1.30	0.73-2.31	1.91	0.92-3.94
No (ref)	0.96		1.00	--	--	--

Note: All percentages are weighted proportions; Significance levels: * p<0.05, ** p<0.01 and ***p<0.001

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Table 4: Family Functioning on Delayed for CSHCN

	Bivariate Analysis				*Multivariate Analysis*	
Independent variables	*Weight (Yes %)*	χ^2	*OR*	*95% CI*	*OR*	*95% CI*
Positive coping with parenthood		5.43*				
Yes	15.7		0.52*	0.30-0.91	0.86	0.48-1.53
No (ref)	2.0		1.00	--	--	--
Family problems paying medical bills		82.1***				
Yes	8.8		4.11***	2.99-5.66	2.17***	1.52-3.09
No (ref)	8.9		1.00	--	--	--
Parental social support		6.22*				
Yes	13.8		0.64**	0.45-0.91	0.95	0.63-1.43
No (ref)	3.9		1.00	--	--	--
Frustration		0.65***				
Yes	15.3		10.4***	6.80-15.8	7.68***	5.06-11.6
No (ref)	2.4		--	--	--	--

Note: All percentages are weighted proportions; Significance levels: * p<0.05, ** p<0.01 and ***p<0.001

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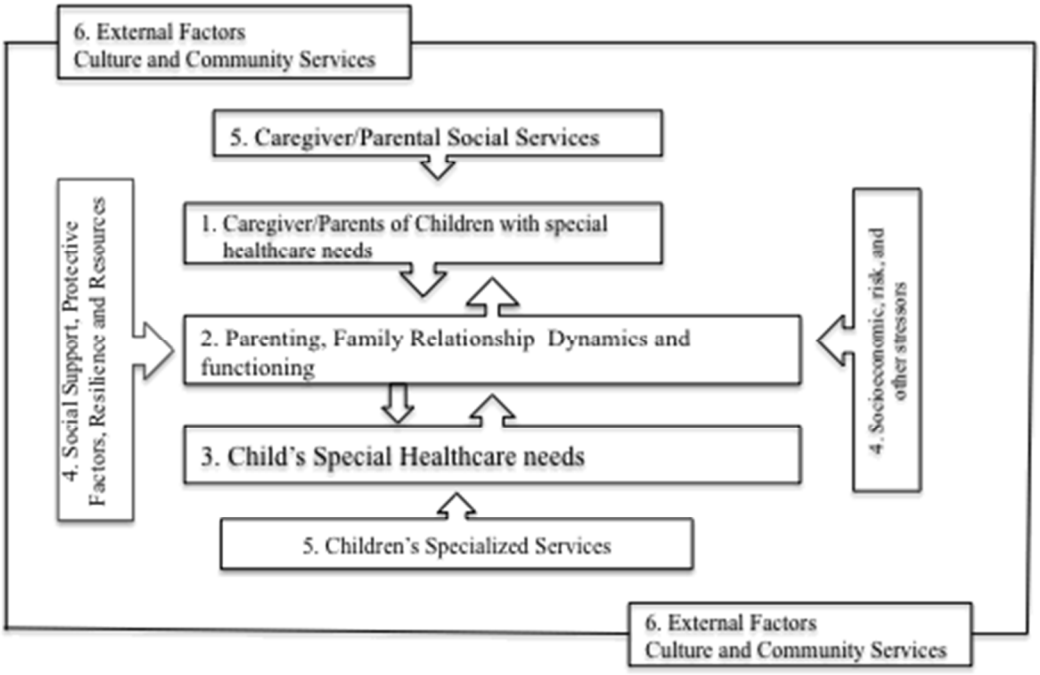

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