

Running head: DISPARITIES IN COPING AMONG PARENTS OF CHILDREN WITH
SPECIAL HEALTH CARE NEEDS

DISPARITIES IN COPING AMONG PARENTS OF CHILDREN WITH SPECIAL HEALTH
CARE NEEDS

by

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Abstract

Significance: Caring for a child with special health care needs requires increased emotional and physical resources from parents. Many parents do not have access to vital resources essential to caring for these children without facing difficulties. To maintain wellness of both the parent and the child, parents of children with special health care needs (CSHCN) must find positive ways to cope with the challenges presented to them.

Research Question: How do parents of CSHCN of Black and Other races differ from their White counterparts on measures of family centered care, care coordination, and financial strain?

Methodology: A secondary analysis of the data from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) was conducted. Chi-square tests, crosstabulations, and logistic regression analysis were performed. Variables included family centered care, financial strain, and care coordination.

Results: Black families and families of other races reported achieving the aspects of family centered care and care coordination at lower rates than their White counterparts, but White families reported experiencing more financial strain. However, the statistical analysis showed that a factor other than race is responsible for the differences in responses.

Implications: By identifying and analyzing different coping mechanisms among racial groups, the nurse can be more culturally aware in the way he/she educates, assists, and enhances coping among parents with CSHCN.

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Background/Significance

Caring for a child with special health care needs can be very taxing for parents. Many parents do not have access to all the resources necessary to properly care for these children without facing difficulties. No matter what kind of struggles they face, parents must find a way to cope. To make a positive impact in the lives of these families, it is important to single out the challenges faced and ways to cope with them. After identifying these key elements, it is imperative to ensure that all families have fair access to all the same services. In the National Survey of Children with Special Health Care Needs (NS-CSHCN), many racial disparities were identified amongst access to proven coping strategies. National statistics show that while the outcome of a medical home was successfully achieved in 48.8% of White families, it was not achieved in 66.8% of Hispanic families and 66.5% of Black families (“National Survey of Children with Special Health Care Needs,” 2010). The survey also indicated that only White families were successfully receiving all the needed components of care coordination, at 58.8%. Lastly, it was shown that Hispanic and Black families pay significantly less amount of money out of pocket than White families (“National Survey of Children with Special Health Care Needs,” 2010). These statistics verify the importance of why a lack of equity in quality of care and access to resources must be addressed among all families of children with special health care needs (CSHCN).

Literature Review/Synthesis

Purpose

The purpose of this literature review was to compile information from different studies to understand the factors associated with the stress and coping of parents of CSHCN and to exhibit

how parents from different racial backgrounds cope with having CSHCN.

Search Process

This search was conducted using East Carolina University Laupus Library OneSearch to search databases such as PubMed and CINAHL. Search terms used included “children with special health care needs,” “CSHCN,” “racial disparities,” “parental coping,” “coping strategies,” and “coping effectiveness.” Upon completion of the literature review, the three inclusion categories that stood out to best describe how parents of different racial backgrounds cope with having CSHCN are challenges faced, coping methods, and disparities in care.

Major Findings

Challenges faced. The inability to meet financial, medical service, and home care obligations are common burdens families of CSHCN experience. Over half (56.8%) of the families with CSHCN surveyed reported experiencing financial problems, with 46% of families having to spend more than \$1,000 in out of pocket costs (Kuo, Cohen, Agrawal, Berry, & Casey, 2011). With an average of 11-15 hours per week spent providing direct home care, many households reported that a member had to stop working due to the child’s health status (Kuo et al., 2011). Almost half of families (48.8%) reported at least one unmet medical service need, and 5% reported greater than five unmet medical needs in the past twelve months. Many families also reported having trouble accessing non-medical services as an adjunct to their child’s care (Kuo et al., 2011). Another study approached this topic by comparing the difficulties faced by parents with CSHCN and parents with children with asthma; the most common chronic childhood disease (Thomson et al., 2016). It was shown that parents of CSCHN reported higher levels of social isolation and more financial struggles, including the inability to pay

rent/mortgage and other family members not being able to fill prescriptions or see needed doctors, than families with children with asthma (Thomson et al., 2016). Many would think that these difficulties would constantly dishearten these parents, but many mothers said that they have more problems coping with the social stigma that accompanies having a CSHCN, than the care taking challenges (Green, 2007). Many mothers report that after a period of getting used to their new life, they can find many benefits in caregiving and appreciate their journey (Green, 2007). By identifying the challenges the parents are faced with, it was possible to start focusing on finding possible coping methods.

Coping methods. The three major coping methods identified in the literature review were the medical home, comprehensive care plans, and support models. Defined by The Maternal and Child Health Bureau (MCHB) for use in the NS-CSHCN, a ‘medical home’ must incorporate all five of the following components: usual source of care, personal doctor or nurse, family-centered care, coordinated care, and the ability to obtain needed referrals (Miller, Nugent, & Russell, 2014). Medical homes are important in reducing stress experienced by parents with CSHCN because they greatly aid in the coordination of services required to provide specific needs of the children and their families. With most families spending between 1 and 5 hours arranging care per week, a medical home greatly reduced the impact of this burden. (Miller et al., 2014). A study that focused on the direct relationship of a health care home and parental coping proved a positive correlation (Drummond, Looman, & Phillips, 2011). Medical homes are most effective if all five components are adequately met, so a focus should be put on providing complete medical homes to these patients.

Another coping mechanism highlighted was the importance of CSHCN having a comprehensive care plan, or a road map of care. Both health care providers and parents agreed

that dynamic care plans improved communication and enhanced timely, safe, and coordinated care for the child (Adams et al, 2013). Parents reported feeling more confident and credible during encounters with health care professionals using the care plan (Adams et al., 2013). Overall, comprehensive care plans improved care of the child, which goes hand in hand with coping among parents.

Lastly, a study done in Chicago compared the effects of formal and informal social support with self-rated health, daily somatic symptoms, and C-reactive Protein (CRP) levels, an inflammation marker in the body, among parents of children with an Autism Spectrum Disorder (ASD) (Gouin, Estrela, Desmarais, & Barker, 2016). Results of this study indicated that both formal support services and informal social support were significantly and independently positively related to self-health and lower circulating CRP levels, indicating better coping (Gouin et al., 2016). It was also shown that the more formal support services a parent used, the fewer daily somatic symptoms they experienced (Gouin et al., 2016). As previously referenced, social support can be difficult for parents with CSHCN to acquire, but it is proven to be a positive coping method if possible.

Disparities in care. This literature review revealed three significant articles that focused on comparing how different racial groups cope with having CSHCN. One of these studies specifically compared how parents of Black CSHCN versus parents of White CSHCN reported the receipt of family centered care. Family centered care is an aspect of the medical home and is measured by the following indicators: doctor spends enough time with the parent, doctor listens carefully, doctor is sensitive to parent's values and customs, doctor provides specific information needed by the parent, and the doctor helps the parent feel like a partner in the care of the child (Montes & Halterman, 2011). Parents of Black CSHCN were more likely to report that their

child *sometimes* or *never* received family-centered care. Specifically, fewer parents of Black CSHCN reported that the doctor spends enough time with their child, is sensitive to their values and customs, and makes them feel like a partner in the care of their child (Montes & Halterman, 2011). These racial differences among parents with CSHCN is concerning and must be addressed to improve care of the children and coping among the parents.

To further explore discrepancies in coping mechanisms among different racial and ethnic groups, M. Radzilani-Makatu conducted interviews of Black Tshivenda-speaking parents with CSHCN. Interviews focused on gaining insight into day-to-day living experiences and then answers were analyzed for coping strategies, both positive and negative. Some positive coping strategies identified, which allow parents to work towards improving their situation, are communication, belief in divine intervention, relying on social and religious support, and seeking information (Radzilani-Makatu, 2014). In contrast, negative coping strategies include self-blame, isolation, and self-neglect (Radzilani-Makatu, 2014). This study did not compare these coping strategies to any other group, but it can be inferred that the results hold true despite racial or ethnic background.

The third article compared the effect of intensive care coordination on parental satisfaction among English and Spanish speaking parents. Both the English and Spanish speaking parents were consistent with awarding their highest scores to the questions regarding family-centered care and lowest scores to questions regarding care plans (Hamilton, Lerner, Presson, & Klitzner, 2012). Even though there were no statistically significant differences in the way the parents answered individual questions, it was determined that Spanish speaking parents were more satisfied than English speaking parents (Hamilton et al., 2012).

Research Questions/Aims of the Literature Review

This project aims to answer a few questions to look at this subject holistically. The following questions were asked during the literature review: among families with CSHCN, what challenges do they face daily and how do these parents cope with their specific challenges? Once those questions are answered, the data was analyzed to answer the question: How do parents of CSHCN of Black and Other races differ from their White counterparts on measures of family centered care, care coordination, and financial strain?

Methodology

Sample

The sample comes from the 2009-2010 NS-CSHCN. This includes, “non-institutionalized CSHCN in the US ages 0-17 years old” (“National Survey of Children with Special Health Care Needs,” 2010). The MCHB defines CSHCN as, “Those who have one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” (“Who Are Children with Special Health Care Needs?,” n.d., p. 1). To define race for this study, the derived race of the target child was described as, “White only, Black only, and Other.” Since this is how the different racial groups were categorized in the raw data set that was downloaded and analyzed. The “Other” race category includes Hispanic, Asian, Pacific Islander, Native American, any mixed racial identities, and all other racial responses. The number of responses from each race, respectively, equaled 29,943 (75.6%), 4,147 (10.5%), and 5,499 (13.9%) to total 39,589 (100%) of the responses.

Statistical Analyses

Chi-square analyses and crosstabulations were performed to assess the bivariate association between race, and the reported achievement of family centered care, care coordination, and absence of financial strain. A logistic regression analysis was performed on the summed family centered care components to combine the five questions addressing family centered care into one variable. Due to the large sample size, the statistical significance parameter was set at $p=0.005$. SPSS was the statistical program used to analyze the data.

Results

Significant relationships were determined for all independent variables: family centered care, care coordination, and financial strain. Table 1 shows the proportions of responses across the racial groups for all the discussed variables. Table 2 shows the differences in means of responses regarding the components of family centered care within the racial groups. Black families and families of Other races are far less likely to report achieving satisfactory *family centered care* than White families. However, 67.4% of White parents, 15.1% of Black parents and 17.5% of parents of Other races reported being without family centered care ($p=0.000$).

When answering the question regarding *financial strain*, 75.4% of White families, 9.8% of Black families, and 14.8% of families of Other races reported that having a CSHCN caused financial problems for the family, while 75.7% of White parents, 10.6% of Black parents and 13.6% of the Other race families that answered the survey reported that caring for their CSHCN did not cause financial problems for the family ($p=0.005$). Fewer Black and Other race families reported having financial strain because of having a CSHCN than White families.

More Black families and families of Other races reported wanting extra help *coordinating care* than White families. Of the parents who reported needing extra help with *care coordination* among different health care providers or services, 67.8% were White, 14.4% were Black, and 17.7% were of Other races. Meanwhile, 77.4% of White parents, 9.6% of Black parents and 13.0% of parents of Other racial groups reported not needing extra help coordinating care ($p=0.000$). There was not a significant difference found among the racial groups in responses to the question, “Does a doctor or someone in a doctor’s office provide help in arranging or coordinating care among the different doctors or services the child uses?” ($p=0.040$).

After performing a linear regression for the variables that measure family centered care, the Cox and Snell R^2 value equaled 0.000, suggesting that race is not the factor responsible for the difference in responses.

Table 1

Parental Perception of Achieving Family Centered Care, Care Coordination, and Absence of Financial Strain

Variable			White	Black	Other	Total	χ^2	df	p value
Family centered care	Yes	N	21,275	2,217	3,233	26,725	717.007	2	.000
		%	79.6%	8.3%	12.1%	100%			
	No	N	8,309	1,860	2,157	12,326			
		%	67.4%	15.1%	17.5%	100%			

Financial strain	Yes	N	6,022	782	1,183	7,987	10.802	2	.005
		%	75.4%	9.8%	14.8%	100%			
	No	N	23,870	3,355	4,300	31,525			
		%	75.7%	10.6%	13.6%	100%			
Care Coordination: Has help with care coordination from a doctor or someone at a doctor's office	Yes	N	4,384	728	981	6,093	6.436	2	.040
		%	72.0%	11.9%	16.1%	100%			
	No	N	1,508	205	350	2,063			
		%	73.1%	9.9%	17.0%	100%			
Care Coordination: Needs additional help with care coordination	Yes	N	4,107	875	1,075	6,057	259.886	2	.000
		%	67.8%	14.4%	17.7%	100%			
	No	N	25,542	3,169	4,308	33,019			
		%	77.4%	9.6%	13.0%	100%			

Table 2

Differences in Means of Responses to Components of Family Centered Care

Derived. Race of target child (I)	Derived. Race of target child (J)	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval (Lower Bound)	95% Confidence Interval (Upper Bound)
White only	Black only	0.1583*	0.01002	0.000	0.1343	0.1823
White only	Other	0.1409*	0.00887	0.000	0.1196	0.1621
Black only	White only	-0.1583	0.01002	0.000	-0.1823	-0.1343
Black only	Other	-0.0174	0.01244	0.484	-0.0472	0.0124
Other	White only	-0.1409	0.00887	0.000	-0.1621	-0.1196
Other	Black only	0.0174	0.01244	0.484	-0.0124	0.0472

Discussion

The data from this study showed a statistically significant difference in the responses between White and Black parents of CSHCN, and the responses of White parents and parents of Other racial identities. However, for most of the variables, there was not a statistically significant difference in the responses between Black parents and parents of Other racial identities. Even though most of these results are statistically significant across racial groups, the Cox and Snell R^2 value suggests that some factor other than race is responsible for the differences in responses.

An interesting finding was that Black families and families of Other races were less likely to report experiencing financial difficulty due to their child's special health care needs than White families. It was speculated that public health insurance requires lower out of pocket payments than private insurance providers. If Black and Other families have a higher rate of public health insurance use, they do not need to pay as much money out of pocket, and are bound to say that they do not experience a financial burden.

Another finding that warrants an explanation and further investigation is the difference in the responses to the question that asks if a doctor or someone from the doctor's office helps the parent coordinate care for the CSHCN. There was not a statistically significant difference across racial groups. However, there was a statistically significant difference in the responses to the question that asked about needing more help with care coordination, as White families more frequently reported not needing extra help than Black families and families of Other races. This could suggest that White families are receiving care coordination assistance from sources other than the doctor's offices, or that they are receiving better care coordination services from their doctor's offices than Black and Other racial families.

Two additional studies were found that offered possible other explanations for the disparities in responses. Porterfield and McBride conducted a secondary data analysis of the 2001 NS-CSHN to address the relationship between the mother's education level and socioeconomic status (SES) to the perceived need for and access to care for the CSHCN (2007). They concluded that if the parents or caregivers recognized a need, the child most likely received it. If the need was recognized, but the child still went without, the two main reasons were due to the service(s) costing too much or there was a "health plan problem" (McBride & Porterfield, 2007). The authors did not define a "health plan problem," but it is presumed they are referring to health insurance. The study also determined that parents of lower education and SES had a lower perceived need for specialized health care services, therefore their child did not receive them (McBride & Porterfield, 2007).

The second study, by Pickard and Ingersoll, looked at the association between parental SES and the use of services for their child with Autism Spectrum Disorder (ASD) (2015). It found that both parents of high and low SES were aware of their child's needs. However, parents of low SES reported needing more information about what services were available and how to attain them, while parents of higher SES reported a need for "higher quality services" (Ingersoll & Pickard, 2015).

It is clear to see that parental SES and education level have a heavy impact on the type and quality of services they seek for their children. The gap in understanding the need for and access to services, however, might have an impact on their access to the supportive coping mechanisms examined in this study (family centered care, care coordination, and financial strain).

Another possible explanation for the discrepancies in responses is the severity of the child's diagnosis. For instance, many of the children accounted for in this survey suffer from asthma (35.3%) ("National Survey of Children with Special Health Care Needs," 2010). These children may not need as intense of assistance with care coordination and family centered care or as expensive therapies and services as children with more severe conditions, such as cerebral palsy (1.6%), cystic fibrosis (0.3%), or muscular dystrophy (0.3%) ("National Survey of Children with Special Health Care Needs," 2010). It is important to look at these other possible variables in relationship to the identified racial disparity in the achievement of the identified supportive coping mechanisms for parents of CSHCN.

Limitations

There are a few limitations to this study. First, because this was a secondary data analysis of a national survey, we were not able to control how the survey questions were asked. Therefore, we had to perform a search of the questions to find ones that seemed to most reflect what was discovered during the literature review. Additionally, since the survey adopted a system of self-reporting of race, we had to choose the best option for race. We do not know if parents identify as other races in addition to what they reported. Future research should include more specific parameters for grouping of racial identities. Lastly, the extremely large sample size drastically increases the chance of finding statistical significance. Future research should include effect size to show a true comparison of the responses between the racial groups.

Clinical Application

Regardless of race, SES, education level, or the child's clinical diagnoses, every family should be able to obtain the highest quality of care for their CSHCN. By recognizing exactly

which factors most greatly enhance parental coping, nurses, doctors, and other health care providers can be intentional with their plan of care to include interventions that incorporate these elements, such as care coordination and family centered care. Doctor's offices should provide consistent and exceptional education to all parents of CSHCN concerning their options of care, complimentary services available, and monetary assistance programs. Very seldom will a parent disregard a treatment that will help their child if they are aware of it, have access to it, and can afford it. With education and advocacy, we can not only enhance the child's quality of life, but their parent's ability to cope with having a CSHCN.

Conclusion

There were some clear differences along racial lines in the aspects of parental coping, but the statistical analysis indicates that race is not the most important factor. We do not currently know what the most important factor for the inconsistency in responses is, and further research is needed.

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