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PUBLIC HEALTH | RESEARCH ARTICLE

Urban vs. rural differences in insurance coverage and impact on employment among families caring for a child with cerebral palsy

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Abstract: *Background:* The purpose of this study was to examine urban vs. rural differences on the relationship between family contextual variables and adequacy of insurance coverage and impact on employment for among families with a child with Cerebral Palsy from a nationally representative sample. *Methods:* A retrospective, observational study was carried out using data from the National Survey of Children with Special Healthcare Needs. *Results:* A total of 744 participants reported as having a child with a diagnosis of Cerebral Palsy and were included in the sample. Logistic regression analyses, adjusting for urban and rural setting revealed different predictors of adequacy of insurance coverage and impact on employment. Among urban respondents, three variables with odds ratios ranging from 1.33 to 1.58 served as protective factors, increasing the likelihood of adequate insurance coverage. Four variables with odds ratios ranging from 1.41 to 1.79 decreased the likelihood of negatively impacting employment. Among rural families, there was only one significant protective factor for adequacy of insurance coverage (odds ratio 1.80) and one for decreasing the chances of impact on employment (odds ratio 2.53). *Conclusion:* Families in rural areas caring for a child with CP have few protective factors for adequate insurance coverage and impact on familial employment.

ABOUT THE AUTHORS

Braydon J. Schaible, MPH, is currently a doctoral student in the Jiann-Ping Hsu College of Public Health at Georgia Southern University. He completed his practicum experience for his MPH under the supervision of Gavin Colquitt, EdD, an associate professor in the School of Health and Kinesiology at Georgia Southern University. Li Li, PhD is a Research Professor of Biomechanics in the School of Health and Kinesiology at Georgia Southern University. Manuela Caciula, PhD is an Assistant Professor of Exercise Science at Georgia Southern University and Noelle Moreau, PhD, PT is an Associate Professor in the Department of Physical Therapy at Louisiana State University Health Sciences Center. Drs Colquitt, Li, Caciula, and Moreau comprise an interdisciplinary team examining school- and community-based health interventions for young people with Cerebral Palsy in rural areas.

PUBLIC INTEREST STATEMENT

Cerebral palsy (CP) is the most common movement disability among children. Children with CP have complex medical needs and require access to specialized services. Individuals in rural areas often lack access to both basic and specialized care. As families caring for a child with CP must often provide direct support and care while also coordinating specific medical services to meet the needs of the child, families in rural areas may face an additional burden. These tasks can often have a negative impact on other areas of the such as employment, which in turn can also impact insurance coverage. We examined data from a large, national sample to measure this potential impact. We found that urban families have more protective factors that include personal and community-based resources to increase the likelihood of families have adequate insurance coverage and preventing a negative impact on familial employment.

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1. Introduction

Children with special healthcare needs (CSHCN) living in rural areas face a convergence of risk factors associated with their chronic conditions and limitations to receiving appropriate care. The federal Maternal and Child Health Bureau defines children with special health care needs (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" (McPherson et al., 1998, p. 138). Rural communities possess a myriad of limitations that have been described as 'rural limits,' a lack of specific resources which are connected to geographic location and low socioeconomic status (Skinner & Rosenberg, 2006). Young people in rural areas are at greater risk of many chronic diseases due to poor health outcomes (Shriver et al., 2011). Compared to their typically developing peers, children with special health care needs (CSHCN) are less likely to receive routine and preventative care (Van Cleave & Davis, 2008). Families caring for a CSHCN in rural areas face many barriers to obtaining support and health services due to a lack of resources (Iezzoni, Killeen, & O'Day, 2006). In rural areas, CHCSN often lack proper care due to inadequate insurance coverage (Skinner, Slifkin, & Mayer, 2006). Among CSHCN with inadequate insurance coverage, those in rural areas often underutilize available healthcare services due to a lack of specialized providers (McManus, Lindroth, Richardson, & Rapport, 2015). When coverage is improved, CSHCN in rural areas are still faced with barriers to access services such as lack of guidance, fewer service providers, and higher costs for specialized services (Dew et al., 2013).
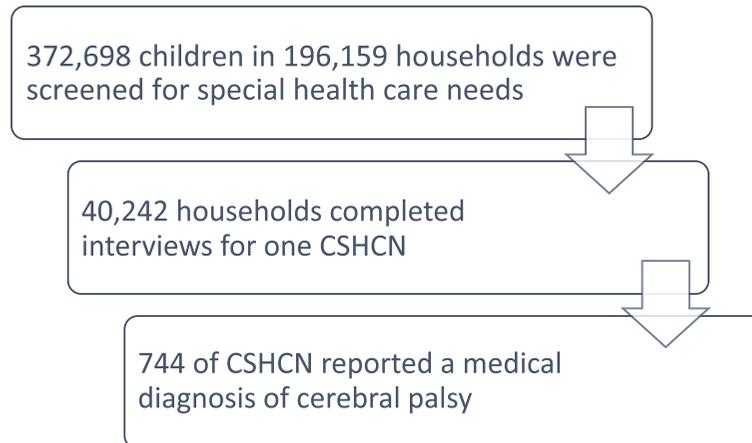
Within the larger population of CHSCN, young people with cerebral palsy (CP) have more unmet needs due to the complexity and potential severity of the disability (Jackson, Krishnaswami, & McPheeters, 2011). CP refers to multiple neurological disorders that result in permanent but non-progressive motor impairment (Health, 2013). The prevalence of the disability has remained stable over time, averaging 2.11 in 1,000 live births (Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013). CP is a developmental disorder caused by traumatic brain damage. Symptoms include "disturbances in sensation, perception, cognition, communication, and behavior, epilepsy and secondary musculoskeletal problems" (Rosenbaum et al., 2007). The accompanying symptoms associated with CP result in the need for specialized services, placing children with CP within the larger category of CSHCN.

Urban vs. rural differences in the impact of CP on the family and access to resources have been observed in many contexts outside the United States (US). A comparison of two cohorts of preschool aged children with CP between two countries indicated that lack of resources was correlated with poor cognitive and motor development (Benfer et al., 2014). The economic burden of CP on rural families in China is greater due to indirect costs such as transportation to obtain specialized treatments (Wang et al., 2008). Parents of children with CP in rural regions of Australia experienced a disconnectedness from healthcare providers due to limited resources (Hayles, Harvey, Plummer, & Jones, 2015). In the United Kingdom, the environmental context can influence physical activity participation among children with CP as much as physical and cognitive function (Hammal, Jarvis, & Colver, 2004). A recent review of CP research conducted in Africa indicated that most rural areas lack healthcare service providers trained to care for children with CP (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014). In the US, there is a paucity of research on the impact of context on caring for a child with CP. Parents of children with CP in the US often experience lack of access to funding, opportunities for employment, and few support services, all of which can negatively impact the quality of life of both the child and the parent (Davis et al., 2010). However, the relationship between context (i.e. urban vs. rural) and these factors has not been examined.

The purpose of this study was to examine urban vs. rural differences in impact on parental employment and access to insurance coverage among families of children with CP using data from a

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Figure 1. Survey design of NS-CSHCN.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey (2011).

372,698 children in 196,159 households were screened for special health care needs

40,242 households completed interviews for one CSHCN

744 of CSHCN reported a medical diagnosis of cerebral palsy

national sample of children with CSHCN. Results could have implications for public health practitioners and community-based service providers who care for CSHCN.

2. Materials and methods

2.1. Setting and participants

The data was taken from the National Survey of Children with Special Health Care Needs (NS-CSHCN) (Bramlett et al., 2014). The NS-CSHCN was designed to examine state- and national-level estimates of CSHCN and was employed via a cross-sectional sampling of households in the United States (US) with at least one child with a special healthcare need between the ages of 0–17. The survey was conducted using a random-digit-dial (RDD) sampling of landline telephones with a supplement of RDD of cellular phone numbers. Telephone numbers generated in the randomized list were called and screened for status as a US resident and having a child between the ages of 0–17. All households were screened for potential respondents using the CSHCN Screener (Bethell et al., 2002). The survey was conducted in all 50 states as well as the District of Columbia. Information was gathered regarding demographics, the impact of the child's health on his/her family, access to services and health care, insurance information for the child, as well as a number of other health related topics. Of 40,242 completed interviews from 2009 to 2011, 744 reported as having a child with a diagnosis of CP and were included in the sample (see Figure 1). Participant locale was classified based on the National Center for Health Statics Urban/Rural Classification Scheme of living in either a metropolitan statistical area (MSA; urban) or non-MSA area (rural) (Ingram & Franco, 2012). Verbal consent was obtained from each survey respondent prior to the start of the questionnaire. Ethical approval for this study was issued by the Georgia Southern University Institutional Review Board.

2.2. Insurance coverage, impact on employment, and family contextual variables

All variables were taken directly from the 2009–2010 NS-CSHCN Indicator and Outcome Variables SAS Codebook (Child and Adolescent Health Measurement Initiative, 2012). Most variables were composite measures of questions determined using pre-established criteria. A number of variables with multiple levels were collapsed into binary indicators based on specific criteria for each measure as defined by Maternal and Child Health Bureau (MCHB) Core Outcomes for Systems Care and key health indicators (Child and Adolescent Health Measurement Initiative, 2012). For example, indicator1_09, a variable representing unmet needs for health services or equipment (none, one, two or more), was collapsed into a binary variable determining whether or not there the family experienced an unmet need for health services or equipment. Validity was enhanced through data screening and sampling weights which based on three sets of weights: household, child screener, and child interview. Sixteen adjustments were then made to the base weights. For a detailed explanation of sampling weights and validity checks see (Bramlett et al., 2014).

2.2.1. Adequacy of insurance coverage

This subscale was comprised of three questions pertaining to insurance coverage. First, the respondent was asked to respond with never, sometimes, usually, or always to the following questions: "Does your CSHCN's health insurance offer benefits or cover services that meet his/her needs?"; "Are the costs not covered by your CSHCN's health insurance reasonable?"; and "Does your CSHCN's health insurance allow him/her to see the health care providers he/she needs?" A child was deemed to have inadequate insurance of the respondent answered never or sometimes to each of the three questions.

2.2.2. Impact on family work life

The following two yes or no questions were asked regarding family member's employment: "Have you or other family members stopped working because your CSHCN's health conditions?" and "Have you or other family members cut down on the hours you work because of your CSHCN's health conditions?" If respondents answered yes to either of the two questions, then their employment was classified as negatively affected.

2.2.3. Covariates

The variable for *missed school days* had four levels: 0–3, 4–6, 7–10, and 11 or more missed school days. We dichotomized this variable based on the median number of days represented in the survey to represent 0–6 missed school days or 7 or more missed school days. Respondents were asked a series of questions to determine *unmet needs* of the child regarding health care services or equipment in the past 12 months. This was dichotomized represent whether or not the child had any unmet needs for health services or equipment. Questions regarding the *out of pocket expenses* were dichotomized into less than $1000 and more than $1000. The *family financial burden* variable was determined based on respondents' response to: "Has your CSHCN's health conditions caused financial problems for your family?" The variable representing the family's role in *shared decision-making* for the child's optimal health was created using answers regarding the following four questions: "How often did doctors discuss range of treatment options?", "How often did doctors encourage you to raise concerns?", "How often did doctors make it easy to ask questions?", "How often did doctors consider and respect your thoughts regarding treatment options?" Responses included never, sometimes, usually, or always to each questions, and was characterized as shared decision-making if the respondents answered usually or always to all four questions. The *medical home* composite measure was determined based on five subcomponents comprised of criteria from the MCHB based on whether or not the child: (1) receives care that is family-centered, (2) has a usual source for both sick and preventive care, (3) receives referrals without difficulty (4) is seen by a personal healthcare provider, and (5) receives care that is effectively coordinated (Strickland et al., 2004). There were a series of questions used to determine the CSHCN's *ease of access to community based services*. The questions asked if families experienced difficulties, delays, or frustration due to lack of eligibility, lack of service availability, issues related to costs, or lack of information. Responses of never/sometimes experiencing frustration or reporting no difficulties or delays met the criteria for ease of access. The variable representing *unmet needs for family support services* was created by asking respondents whether or not they needed and received respite care, genetic counseling, and mental health care/counseling. Responses, which reported a need that did not correspond with receipt of care was classified as one unmet need for family, support services. The *total hours per week that they spent providing care* for their child was categorized into four levels of hours per week: <1, 1–4, 5–10, ≥11. Two questions asked if the child received preventive medical and/or dental care in the past 12 months. A "no" response to both indicated no *early and continuous screening for special health care needs*.

2.3. Data analysis

The data-set was subset to 744 observations representing CSHCN with CP. There were a number of observations with missing data for certain variables. This was dealt with in two ways. First, descriptive statistics were obtained using complete case analysis. Using SAS's proc freq (SAS Institute, Cary, NC), χ^2 tests of association were produced to determine which variables were significantly associated with MSA status. Two outcome variables were then selected: adequacy of insurance coverage

and effect of child's health on family members' work lives. Once preliminary analysis using complete cases was finished, we then performed multiple imputation (5 imputations) using fully conditional specification (FCS) with SAS's "mi" procedure (SAS Institute, Cary, NC). Logistic regression was then performed, creating separate models for both previously mentioned outcome variables while controlling for additional covariates, both of which included the urban vs. rural variable. SAS's "mianalyze" procedure (SAS Institute, Cary, NC) as well as backwards elimination for model selection were used to determine the final models for each outcome. Once the final models were determined, we examined urban-adjusted and rural-adjusted models for each outcome. The two missing data approaches that we considered were multiple imputation using FCS and the expectation maximization algorithm, both of which are built to handle missing categorical data under the assumption of missing at random (MAR). However, we followed Peng and Zhu's recommendation and employed multiple imputation (Peng & Zhu, 2007). The data-set contained 28.9, 3.9, 0.5% missing observations for our three variables of interest (urban/rural setting, adequacy of insurance coverage, and impact on family members' work lives), respectively.

3. Results

Most respondents lived in an urban (78%) compared to rural (22%) area. Most children families cared for a male (58%) vs. female (44%) child with CP. Ethnic representation of the sample were as follows: 67.88% white, 12.23% black (non-Hispanic), 11.56% Hispanic, and 8.33% other (non-Hispanic). The mean age of the overall study population was 9.75 (SD = 4.65), while the mean age of those living in urban and rural settings was 9.74 (SD = 4.50) and 10.17 (SD = 4.69), respectively. Additional family demographics are presented in Table 1.

Univariate logistic regression analyses were conducted on all possible covariates, for each outcome. In order to reduce the risk of overfitting the models, only variables with statistically significant univariate *p*-values ($p < 0.05$) were selected for the full models. After variable selection based on the univariate results, models were built using a backwards elimination method with a *p*-value of <0.05 required to stay in the model. Variables removed during the process were added back in at the end, individually, to make certain their removal from the model was necessary. Interaction terms were tested for each model, however no interactions were significant.

The adjusted model provided results for urban and rural families. Tables 2–5 represent statistically significant results of the two models. In both tables, odds ratios greater than one served as protective factors- increasing the chance of either having *adequate insurance coverage* or no *impact on employment of the family*- while odds ratios less than one indicate variables which resulted in decreasing the likelihood of having adequate coverage or employment affected. Among families living in rural areas, 67.86% had adequate insurance coverage compared to 59.49% among urban families.

Our analysis showed significant differences after stratified by urban and rural families (Table 6). After controlling for education level of the child's parents, five variables were significant predictors of *adequate insurance coverage* among urban families compared to two significant predictors for rural families. Our results showed significant differences among urban and rural families concerning the adequacy of the child's current insurance coverage. There were five significant predictors of *adequacy of insurance coverage* among urban respondents: missed school days, financial resources, and access to services (see Table 6). However, only minimal out-of-pocket expenses (<$1000 for the year) and family-doctor cooperative decision-making for the child's optimal health were significant predictors in the model adjusting for a family living in a rural setting. Among rural families, when families are not involved in making major decisions for the child, they are less likely to have adequate insurance coverage.

Table 1. Demographics			
Variable	**Level**	**N = 744**	**%**
Urban/rural living status	Rural	118	22.3
	Urban	411	77.7
CSHCN age 0–17 years who have a little or a lot of difficulty with one or more activities or participation	No difficulties with activities	13	1.7
	A little or a lot of difficulty with one or more activities	731	98.3
CSHCN age 18 months–17 years who have a little or a lot of difficulty with one or more emotional or behavioral factors	No emotional or behavioral difficulties	211	29.1
	A little or a lot of difficulty with one or more emotional or behavioral factors	515	70.9
CSHCN age 0–17 years who have a little or a lot of difficulty with one or more body functions	No difficulties involving bodily functions	150	20.2
	A little or a lot of difficulty with one or more bodily functions	594	79.8
Gender	Male	431	57.9
	Female	313	42.1
Age group	0–5 years old	161	21.6
	6–11 years old	291	39.1
	12–17 years old	292	39.2
Race/ethnicity	Hispanic	86	11.6
	White, non-Hispanic	505	67.9
	Black, non-Hispanic	91	12.2
	Other, non-Hispanic	62	8.3
Poverty level (% of federal poverty level)	0–99% FPL	157	21.1
	100–199% FPL	155	20.8
	200–399% FPL	255	34.3
	400% FPL or greater	177	23.8
Family structure	Parent household biological or adopted	486	66.1
	2 parent stepfamily household	52	7.1
	Mother only household	132	18.0
	Other family structure household	65	8.8
Highest education level attained of any adult in the family	Less than high school	37	5.0
	High school grad	136	18.3
	More than high school	571	76.7

Among urban families, 64.46% of families had at least one member cut back their work hours or stop working altogether in order to care for their child with CP compared to 50.85% of families in rural areas. Our analysis indicated significant differences between families with children with CP living in urban and rural settings concerning the impact that the child's health had on family member's work lives. There were six significant variables predicting the impact on employment of family members for families living in an urban setting categories relating to missed school days, financial burden, and access to services (see Table 7). However, only a low financial burden and less time spent caring for the child were significant predictors among rural families.

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Table 2. Logistic regression model for the probability the child has adequate insurance coverage

Variable	Odds ratio	Odds ratio 95% confidence limits		*p*-value
Urban/rural variable (reference = urban)				
Located in a rural area	1.21	0.96	1.54	0.1096
Education level of parents (reference = More than high school)				
High school graduate	1.58*	1.09	2.28	0.0152
Less than high school	0.55*	0.33	0.92	0.0238
Missed school days (reference = 7 or more missed days)				
0–6 missed days	0.74*	0.62	0.89	0.0013
Unmet needs for care (reference = at least 1 unmet need)				
No unmet needs for services/ equipment	1.23*	1.03	1.47	0.0235
Out-of-pocket expenses (reference = more than $1000)				
Less than $1000	1.60*	1.34	1.91	<0.0001
Family financial burden (reference = having financial problems)				
No financial problems due to child's health	1.27*	1.06	1.52	0.0092
Family is partner in decision making for child's optimal health (reference = MEETS criteria)				
Does not meet criteria	0.79*	0.65	0.96	0.0168
Medical home composite measure (reference = MEETS criteria)				
Care does not meet medical home criteria	0.82*	0.67	0.99	0.0364
Ease of access to community-based services (reference = MEETS criteria)				
Does not meet criteria	0.75*	0.62	0.91	0.0027

*Statistically significant at *p* < 0.05

Table 3. Urban/rural-adjusted odds ratios for variables in "adequacy of insurance coverage" model

Variable	OR*	Lower 95% CI	Upper 95% CI
Urban			
Missed school days 0–6	0.73*	0.59	0.91
No unmet needs for support services	1.33*	1.08	1.64
<$1000 out-of-pocket expenses (reference=>$1000)	1.58*	1.25	1.94
No family financial burden due to child's health	1.29*	1.05	1.59
No easy access to community based services	0.71*	0.57	0.89
Rural			
Family is NOT a partner in decision-making for child's optimal health	0.57*	0.36	0.90
<$1000 out-of-pocket expenses	1.80*	1.18	2.74

*Statistically significant at *p* < 0.05.

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Table 4. Logistic regression model for the probability that family member's employment is not affected due to the child's health				
Variable	**Odds ratio**	**Odds ratio 95% confidence limits**		**p-value**
Urban/rural variable (reference = urban)				
Located in a rural area	2.09*	1.35	3.23	0.0011
Family structure (reference = parent household, biological or adopted)				
Family structure—2 parent stepfamily household	1.85	0.95	3.60	0.0722
Family structure—mother only household	1.30	0.80	2.11	0.295
Family structure—other family structure	2.72*	1.51	4.90	0.0009
Race (reference = other, non-Hispanic)				
Race—black, non-Hispanic	0.86	0.40	1.83	0.6928
Race—Hispanic	0.33*	0.15	0.72	0.0057
Race—white, non-Hispanic	0.59	0.32	1.10	0.0974
Missed school days (reference = 7 or more missed days)				
Missed school days—0–6 missed days	1.89*	1.24	2.88	0.0036
Unmet needs for family support services (reference = one or more unmet needs)				
	2.24*	1.30	3.84	0.0035
Family financial burden (reference = financial problems due to child's health)				
No financial problems due to child's health	2.41*	1.66	3.51	<.0001
Hours per week providing care (reference = less than 1 h)				
1–4 h per week	0.76	0.44	1.33	0.3364
5–10 h per week	0.42*	0.21	0.85	0.0157
11+ h per week	0.35*	0.21	0.60	0.0001
Medical home composite measure (reference = care MEETS medical home criteria)				
Care does not meet medical home criteria	0.60*	0.42	0.86	0.0047
Early and continuous screening for special health care needs (reference = MEETS criteria)				
Does not meet criteria	1.99*	1.32	2.98	0.001

*Statistically significant at *p* < 0.05.

Table 5. Urban/Rural-adjusted odds ratios for variables in "Adequacy of Insurance Coverage" model			
Variable	**Odds ratio**	**Lower 95% CI**	**Upper 95% CI**
Urban			
Missed school days 0–6	1.42*	1.13	1.79
No unmet needs for support services	1.79*	1.26	2.54
No family financial burden due to child's health	1.56*	1.25	1.96
Hours/week providing care 5–10	0.62*	0.44	0.87
Medical home environment	0.79*	0.63	0.96
No early and continuous screening for special health care needs	1.41*	1.11	1.80
Rural			
No family financial burden due to child's health	2.53*	1.11	5.78
Hours/week providing care 5–10	0.17*	0.04	0.75
Hours/week providing care 11+	0.21*	0.05	0.95

*Statistically significant at *p* < 0.05.

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Table 6. Association of covariates with Urban/rural living status				
Covariate	**Level**	**Urban/rural living status**		***p*-value***
		Rural (*N* = 118)	**Urban (*N* = 411)**	
Activity limitations	Daily activities never affected	5 (17.86)	23 (82.14)	0.279
	Daily activities moderately affected some of time	13 (16.25)	67 (83.75)	
	Daily activities consistently affected, often a great deal	100 (23.81)	320 (76.19)	
Missed school days	<7 missed school days	32 (23.36)	105 (76.64)	0.719
	≥7 missed school days	40 (25.16)	119 (74.84)	
Inconsistently insured	Insured entire year	106 (21.37)	390 (78.63)	0.050
	NOT insured at some point during year	11 (36.67)	19 (63.33)	
Currently uninsured	Currently insured	114 (22.18)	400 (77.82)	0.571
	Currently NOT insured	4 (28.57)	10 (71.43)	
Adequacy of current insurance coverage	Current insurance is NOT adequate	36 (18.37)	160 (81.63)	0.109
	Current insurance IS adequate	76 (24.44)	235 (75.56)	
Unmet needs for care	No unmet needs for 14 specific health care services	68 (21.73)	245 (78.27)	0.712
	At least 1 unmet need for services/equipment	46 (23.12)	153 (76.88)	
Unmet needs for family support services	No unmet needs for specific family support services or did not need	97 (22.93)	326 (77.07)	0.490
	One or more unmet needs for family support services	21 (19.81)	85 (80.19)	
Problems obtaining referral	Needed referral, no problems getting it	56 (25.23)	166 (74.77)	0.858
	Needed referral, YES problems getting it	14 (26.42)	39 (73.58)	
Usual source for sick care	Docs office is usual source for sick care	79 (21.24)	293 (78.76)	0.169
	Clinic, health center or other regular source for sick care	30 (28.85)	74 (71.15)	
	No usual source for sick care or ER, Mexico or no one place most often	9 (17.31)	43 (82.69)	
Personal doctor or nurse	No, does not have a PDN	4 (19.05)	17 (80.95)	0.714
	Yes, has one or more PDNs	114 (22.44)	394 (77.56)	
Family centered care	Does NOT have family centered care	43 (21.94)	153 (78.06)	0.832
	Yes, has family centered care	73 (22.74)	248 (77.26)	
Out-of-pocket expenses	Less than $1000	84 (24.42)	260 (75.58)	0.113
	More than $1000	32 (18.29)	143 (81.71)	
Family financial burden	No financial problems due to child's health	72 (22.64)	246 (77.36)	0.934
	Yes, financial problems	46 (22.33)	160 (77.67)	
Hours per week providing care	Less than 1 h	18 (27.69)	47 (72.31)	0.398
	1–4 h per week	23 (17.83)	106 (82.17)	
	5–10 h per week	18 (25.35)	53 (74.65)	
	11 or more hours per week	52 (22.32)	181 (77.68)	
Impact on family work life	Employment not affected	58 (28.57)	145 (71.43)	**0.007**
	Family member cut back hours or stopped working or both	60 (18.58)	263 (81.42)	
OUTCOME #1: How many children met Outcome #1 on shared decision-making, usually/always on all questions	Did not meet Outcome #1	33 (20.63)	127 (79.38)	0.535
	Met Outcome #1	84 (23.08)	280 (76.92)	

(Continued)

Table 6. (*Continued*)				
Covariate	**Level**	**Urban/rural living status**		***p*-value***
		Rural (*N* = 118)	**Urban (*N* = 411)**	
OUTCOME #2: CSHCN receiving coordinated, ongoing, compre-hensive care within a medical home	Care DOES NOT meet medical home criteria	71 (21.07)	266 (78.93)	0.196
	Care MEETS medical home criteria	44 (26.19)	124 (73.81)	
OUTCOME #3: Families of CSHCN have adequate insurance to pay for the services they need	Did not meet outcome #3	44 (20.47)	171 (79.53)	0.446
	Met outcome #3	71 (23.28)	234 (76.72)	
OUTCOME #4: Number of CSHCN with both preventive medical AND dental visits in the past 12 months	Did not meet outcome #4 criteria	24 (19.83)	97 (80.17)	0.514
	Met outcome #4 criteria	91 (22.64)	311 (77.36)	
OUTCOME #5: How many children met outcome #5, ease of access to service use/ experienced no barriers or difficulties in accessing care?	Did not meet outcome #5	62 (22.46)	214 (77.54)	0.937
	Met outcome #5	55 (22.18)	193 (77.82)	
OUTCOME #6: Transition to adulthood—ages 12–17 only	Did not meet outcome #6	38 (24.05)	120 (75.95)	0.640
	Met outcome #6	10 (27.78)	26 (72.22)	
CSHCN age 0–17 years who have a little or a lot of difficulty with one or more activities or participation	No difficulties with activities	0 (0)	11 (100)	0.073
	A little or a lot of difficulty with one or more activities	118 (22.78)	400 (77.22)	
CSHCN age 18 months–17 years who have a little or a lot of difficulty with one or more emotional or behavioral factors	No emotional or behavioral difficulties	33 (21.02)	124 (78.98)	0.658
	A little or a lot of difficulty with one or more emotional or behavioral factors	82 (22.78)	278 (77.22)	
CSHCN age 0–17 years who have a little or a lot of difficulty with one or more body functions	No difficulties involving bodily functions	19 (18.45)	84 (81.55)	0.294
	A little or a lot of difficulty with one or more bodily functions	99 (23.24)	327 (76.76)	
Gender	Male	73 (24.09)	230 (75.91)	0.253
	Female	45 (19.91)	181 (80.09)	
Age group	0–5 years old	25 (23.15)	83 (76.85)	0.497
	6–11 years old	41 (19.71)	167 (80.29)	
	12–17 years old	52 (24.41)	161 (75.59)	
Race/ethnicity	Hispanic	16 (23.19)	53 (76.81)	0.078**
	White, non-Hispanic	86 (24.86)	260 (75.14)	
	Black, non-Hispanic	13 (16.67)	65 (83.33)	
	Other, non-Hispanic	3 (8.33)	33 (91.67)	
Poverty level (% federal poverty level)	0–99% FPL	39 (31.71)	84 (68.29)	<0.001**
	100–199% FPL	31 (28.97)	76 (71.03)	
	200–399% FPL	38 (21.59)	138 (78.41)	
	400% FPL or greater	10 (8.13)	113 (91.87)	
Family structure	CSHCN in parent household biological or adopted	73 (21.53)	266 (78.47)	0.855
	CSHCN in 2 parent stepfamily household	11 (25.58)	32 (74.42)	
	CSHCN in mother only household	25 (25)	75 (75)	
	CSHCN in other family structure household	9 (21.95)	32 (78.05)	

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Table 6. (*Continued*)				
Covariate	**Level**	**Urban/rural living status**		***p*-value***
		Rural (*N* = 118)	**Urban (*N* = 411)**	
What is the highest education level attained of any adult in the family?	Less than high school	10 (29.41)	24 (70.59)	0.132
	High school grad	28 (28.28)	71 (71.72)	
	More than high school	80 (20.2)	316 (79.8)	

*All *p*-values were calculated using a Chi-Square test.

**Statistically significant at p < 0.05.

Table 7. Univariate logistic regression results					
Covariate	**Level**	**Impact on family work life**		**Adequacy of insurance coverage**	
		Odds ratio (95% CI)	**OR *p*-value**	**Odds ratio (95% CI)**	**OR *p*-value**
Urban/rural living status	Rural	1.75 (1.16–2.65)	**0.008**	1.44 (0.92–2.24)	0.110
	Urban	–	–	–	–
CSHCN age 0–17 years who have a little or a lot of difficulty with one or more activities or participation	No difficulties with activities	3.70 (1.13–12.12)	**0.031**	0.74 (0.22–2.44)	0.620
	A little or a lot of difficulty with one or more activities	–	–	–	–
CSHCN age 18 months–17 years who have a little or a lot of difficulty with one or more emotional or behavioral factors	No emotional or behavioral difficulties	1.54 (1.11–2.14)	**0.009**	0.90 (0.65–1.26)	0.546
	A little or a lot of difficulty with one or more emotional or behavioral factors	–	–	–	–
CSHCN age 0–17 years who have a little or a lot of difficulty with one or more body functions	No difficulties involving bodily functions	2.24 (1.56–3.22)	**<0.001**	1.16 (0.79–1.70)	0.440
	A little or a lot of difficulty with one or more bodily functions	–	–	–	–
Gender	Male	1.11 (0.82–1.50)	0.505	0.93 (0.69–1.27)	0.654
	Female	–	–	–	–
Ages group	0–5 years old	0.77 (0.52–1.15)	0.209	0.92 (0.61–1.38)	0.681
	6–11 years old	0.87 (0.62–1.21)	0.395	0.81 (0.58–1.14)	0.229
	12–17 years old	–	–	–	–
Race/ethnicity	Black, non-Hispanic	1.24 (0.65–2.38)	0.517	1.01 (0.51–2.00)	0.981
	Hispanic	0.47 (0.24–0.95)	**0.034**	1.23 (0.60–2.49)	0.571
	White, non-Hispanic	0.79 (0.46–1.35)	0.385	0.88 (0.51–1.53)	0.652
	Other, non-Hispanic	–	–	–	–
Poverty level (% federal poverty level)	0–99% FPL	1.03 (0.66–1.61)	0.899	1.49 (0.95–2.33)	0.080
	100–199% FPL	1.10 (0.70–1.71)	0.680	1.50 (0.96–2.36)	0.075
	200–399% FPL	1.08 (0.73–1.61)	0.701	1.38 (0.93–2.06)	0.106
	400% FPL or greater	–	–	–	–
Family structure	2 parent stepfamily household	1.99 (1.12–3.54)	0.209	1.07 (0.59–1.94)	0.673
	Mother only household	1.05 (0.71–1.57)	**0.033**	1.02 (0.68–1.53)	0.411
	Other family structure household	2.43 (1.44–4.12)	**0.020**	1.77 (0.98–3.18)	0.079
	Parent household biological or adopted	–	–	–	–

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Table 7. *(Continued)*					
Covariate	**Level**	**Impact on family work life**		**Adequacy of insurance coverage**	
		Odds ratio (95% CI)	**OR *p*-value**	**Odds ratio (95% CI)**	**OR *p*-value**
Highest education level attained of any adult in the family	High school grad	1.15 (0.79–1.69)	0.462	1.89 (1.23–2.90)	**0.003**
	Less than high school	1.43 (0.73–2.79)	0.297	0.89 (0.43–1.88)	0.767
	More than high school	–	–	–	–
Activity limitations	Daily activities moderately affected some of time	2.45 (1.65–3.64)	**<0.001**	1.33 (0.88–2.03)	0.179
	Daily activities never affected	2.78 (1.40–5.51)	**0.003**	2.17 (0.96–4.87)	0.061
	Daily activities consistently affected, often a great deal	–	–	–	–
Missed school days	<7 missed school days	1.52 (1.03–2.25)	**0.035**	1.29 (0.87–1.94)	0.208
	≥7 missed school days	–	–	–	–
Inconsistently insured	Insured entire year	1.18 (0.62–2.25)	0.613	2.12 (0.95–4.75)	0.067
	NOT insured at some point during year	–	–	–	–
Adequacy of current insurance coverage	Current insurance is NOT adequate	0.61 (0.44–0.84)	**0.002**	NA	NA
	Current insurance IS adequate	–	–	NA	NA
Unmet needs for care	No unmet needs for 14 specific health care services	1.75 (1.27–2.41)	**<0.001**	2.42 (1.76–3.33)	**<0.001**
	At least 1 unmet need for services/equipment	–	–	–	–
Unmet needs for family support services	No unmet needs for specific family support services or did not need	3.95 (2.44–6.42)	**<0.001**	2.56 (1.75–3.77)	**<0.001**
	One or more unmet needs for family support services	–	–	–	–
Problems obtaining referral	Needed referral, no problems getting it	1.09 (0.62–1.92)	0.756	1.53 (0.91–2.57)	0.108
	Needed referral, YES problems getting it	–	–	–	–
Usual source for sick care	Clinic, health center or other regular source for sick care	1.01 (0.56–1.84)	0.971	1.78 (0.96–3.29)	0.066
	Docs office is usual source for sick care	1.21 (0.72–2.04)	0.464	1.15 (0.68–1.93)	0.604
	No usual source for sick care or ER, Mexico or no one place most often	–	–	–	–
Personal doctor or nurse	No, does not have a PDN	0.80 (0.35–1.80)	0.584	1.33 (0.56–3.12)	0.516
	Yes, has one or more PDNs	–	–	–	–
Family centered care	Does NOT have family centered care	0.71 (0.52–0.97)	**0.034**	0.58 (0.42–0.79)	**<0.001**
	Yes, has family centered care	–	–	–	–
Out-of-pocket expenses	Less than $1000	2.24 (1.61–3.12)	**<0.001**	3.24 (2.35–4.48)	**<0.001**
	More than $1000	–	–	–	–

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Table 7. (Continued)					
Covariate	**Level**	**Impact on family work life**		**Adequacy of insurance coverage**	
		Odds ratio (95% CI)	**OR *p*-value**	**Odds ratio (95% CI)**	**OR *p*-value**
Family financial burden	No financial problems due to child's health	3.45 (2.46–4.82)	<0.001	2.30 (1.68–3.14)	<0.001
	Yes, financial problems	–	–	–	–
Hours per week providing care	1–4 h per week	0.66 (0.39–1.10)	0.015	0.92 (0.53–1.56)	0.324
	5–10 h per week	0.33 (0.18–0.59)	0.037	0.62 (0.34–1.14)	0.142
	11 or more hours per week	0.23 (0.14–0.37)	<0.001	0.71 (0.43–1.18)	0.350
	Less than 1 h	–	–	–	–
Impact on family work life	Employment not affected	NA	NA	1.64 (1.20–2.26)	0.002
	Family member cut back hours or stopped working or both	NA	NA	–	–
OUTCOME #1: How many children met Outcome #1 on shared decision-making, usually/always on all questions	Did not meet Outcome #1	0.69 (0.50–0.97)	0.032	0.43 (0.31–0.60)	<0.001
	Met Outcome #1	–	–	–	–
OUTCOME #2: CSHCN receiving coordinated, ongoing, comprehensive care within a medical home	Care DOES NOT meet medical home criteria	0.49 (0.36–0.67)	<0.001	0.40 (0.28–0.57)	<0.001
	Care MEETS medical home criteria	–	–	–	–
OUTCOME #3: Families of CSHCN have adequate insurance to pay for the services they need	Did not meet outcome #3	0.63 (0.46–0.86)	0.003	0.00 (0.00–1.97E132)	0.906
	Met outcome #3	–	–	–	–
OUTCOME #4: Number of CSHCN with both preventive medical AND dental visits in the past 12 months	Did not meet outcome #4 criteria	1.63 (1.15–2.32)	0.007	0.97 (0.67–1.39)	0.858
	Met outcome #4 criteria	–	–	–	–
OUTCOME #5: How many children met outcome #5, ease of access to service use/ experienced no barriers or difficulties in accessing care?	Did not meet outcome #5	0.47 (0.35–0.63)	<0.001	0.36 (0.26–0.49)	<0.001
	Met outcome #5	–	–	–	–
OUTCOME #6: Transition to adulthood— ages 12–17 only	Did not meet outcome #6	0.38 (0.20–0.70)	0.002	0.42 (0.20–0.86)	0.018
	Met outcome #6	–	–	–	–

4. Discussion

The results of this study provide insight into the adequacy of insurance coverage and impact on family employment among families caring for a child with CP. Despite a higher percentage of families living in poverty, urban families had more predictors of adequacy of insurance coverage for the child with a diagnosis of CP. Urban children who missed fewer school days and did not have easy access to community-based services were less likely to have adequate insurance coverage. Children with CP require additional visits to healthcare providers, often occurring during the school day. Therefore, it is possible that those children who did not have adequate coverage were more likely to be present at school. In urban areas, it is likely that many services the child needed were located within the larger community, but lack of adequate coverage prevented access. While results indicated that children with no unmet needs and greater financial resources were more likely to have adequate coverage, adequate coverage likely had a reciprocal affect as insurance coverage was affordable for these families and resulted in the receipt of services. Only the cost of out-of-pocket expenses resulted in adequate coverage among rural families. This is likely due to insurance covering the costs of many services which is also evidenced in the literature (Davis et al., 2010; Iezzoni et al., 2006; Skinner & Rosenberg, 2006). Many of these same families did not share in the decision-making process for the healthcare of their child, which also made these families less likely to have adequate coverage. These results could be related to the notion of provider competence or access to

specialists specific to the disability of the child as evidenced in other contexts (McManus et al., 2015). Rural families may experience gaps in communication between primary care physicians or specialists and the decision-making family members of the child. Similar findings have been reported among families caring for a child with an intellectual disability, specifically the relationship between parental involvement in coordination of care, provider competence, and satisfaction with services (Neely-Barnes, Carolyn Graff, Marcenko, & Weber, 2008).

However, it is also possible that families in rural areas without adequate coverage feel powerless when making decisions related to their child's health because of limited options. This is also consistent with previous research on the perceptions of both parents of CSHCN and their service providers in rural areas (Alfonso, Walker, Gupta, Telfair, & Colquitt, 2015; Walker, Alfonso, Colquitt, Weeks, & Telfair, 2016). Better communication between these doctors/specialists and family members will lead to better health decisions for the child which may lead to more adequate insurance coverage overall.

Significant differences were also observed in the model for the outcome variable impact on family member's employment. Despite a higher percentage of families living in poverty, urban families with a child with CP had more protective factors to prevent a negative impact on the employment of the family. Six variables predicted impact on employment for these families. Similar to insurance coverage, parents whose children missed fewer school days were more likely to have their employment impacted. These parents may have less access to coverage, therefore these same children are likely to have fewer doctors' visits. This is supported by the results that the presence of a medical home for the child decreased the chances of impacting employment while those without access to early and continuous screening were more likely to be affected. Among these same families, those who spent at 5–10 h per week providing care for their child were more likely to have their employment affected. Financial resources also mediated the effect on parental employment, as families whose children did not have any unmet needs or those with a low financial burden were less likely to have their employment affected. There were only two significant predictors in the rural-adjusted model, family financial burden and hours per week providing care. Family financial burden was a significant predictor in both adjusted models, however, the odds ratio was nearly a full point higher for the rural-adjusted model suggesting that not having a family financial burden for a family living in a rural area could be a stronger protective factor (in terms of family members not having to quit their jobs or cut back on hours), compared to a family living in an urban area.

Overall, little research has been done examining the impact of caring for a child with CP on parental employment. Stabile and Allin (2012) examined several studies that, taken together, show that having a CSHCN increases the likelihood that the mother (and less often the father) will either curtail hours of work or stop working altogether. Lower parental employment among CSHCN appears to contribute to the children's lower coverage by employer-sponsored insurance. The difference in employer-sponsored insurance coverage between children with and without special needs is no longer significant when children whose parents are not employed full-time are excluded, suggesting that the disparity in employer-sponsored coverage is partly due to less full-time employment among parents of children with special needs (Heck & Makuc, 2000). Caregivers of children with CP also have lower incomes, despite the absence of any important differences in education. The findings are consistent with the idea that the financial burden of caring for a CSHCN results in part from a reduced availability of these parents to work for pay (Brehaut et al., 2004).

As with all studies, this study has its limitations. Firstly, we utilized multiple imputation using conditional specification to impute the missing categorical variables. In this case, the missing values were assumed to be MAR and, thus, multiple imputation using FCS is the best method for dealing with this missing data (Peng & Zhu, 2007). The actual data may not have been MAR, rather missing not at random (MNAR), however, FCS has shown to perform quite well, even under the MNAR assumption (Van Buuren, Brand, Groothuis-Oudshoorn, & Rubin, 2006). Also, due to the smaller sample size of the study population living in a rural locale, the estimates produced by the rural-adjusted models may be slightly inflated compared to the estimates for the urban-adjusted models. Lastly, the survey relies on parental-reporting of the diagnosis of CP and health outcomes, which may cause the estimates to be biased.

5. Conclusions

The implications for this study are multifaceted. First, for families, an inadequate insurance coverage and not being able to maintain employment may contribute to greater distress and affect the family socioeconomic status. Second, service providers, such as physicians and health care professionals should monitor the well-being of families, and ensure that parents' health and mental health needs are impacted. Parental health can have lasting effects on the child's psychosocial adjustment. Also, employers should provide support to CP caregivers and extend the respite care to benefit the well-being of the families and the workplace productivity. Currently, the US has a Medicaid waiver system that allows for some supports for individuals based on the severity of the disability and the amount of support an individual with a disability will need function in the community. The Medicaid Home and Community-Based Services (HCBS) 1915(c) waiver is the largest program that provides services in the areas such as support and service coordination, respite, and personal care. However, many families with a CSHCN fail to utilize available services due to additional barriers such as lack of transportation (Friedman & Rizzolo, 2016). This barrier is exacerbated in rural areas (Walker et al., 2016). Additionally, policies related to the 1915(c) waiver are determined by individual states.

The findings of the current study imply that several variables were related to factors that could be solved by means other than increased income and funding to families. This highlights the need for community-based service which can mediate the impact of caring for a child with CP on insurance adequacy. Public health policymakers should place an additional focus on the ability of community-based healthcare providers to care for CSHCN.

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