A Mixed Methods Analysis of the Place-Related Risk and Protective Factors for Hospital Utilization among Children with Complex Chronic Conditions

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Abstract

Purpose: Children with complex chronic conditions (CCC) have high health care needs and utilization. The purpose of this study was to identify place-related risk and protective factors associated with hospital utilization among children with CCC.

Methods: A mixed methods study was conducted to generate a risk profile of place-related factors associated with hospital utilization. The quantitative phase of the study consisted of retrospective review of 216 urban hospital medical records of infants and young children with CCC. The qualitative phase of the study included interviews with parents/caregivers and focus groups with health care providers (HCPs) of children with CCC. Results from multiple regression modeling and directed content analysis were merged using a side-by-side table organized by ecological level.

Findings: Place-related risk and protective factors on multiple ecological levels were identified. Key place-related factors associated with hospital utilization were more complex conditions, positive relationships with HCPs, more parent/family resources, and having fewer place-related resources.

Conclusions: The results of this study suggest patterns of health care utilization among infants and young children with CCC are influenced by place-related factors. Parent relationships with HCPs and comfort with care, hospital resources, and parent resources determine location of care. Results of this study also imply place-related disparities in access to care, especially among children in smaller metropolitan areas and rural-dwelling children.

Keywords: rural population; rural health services; infant; child, preschool; chronic disease

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Children with complex chronic conditions (CCC) are a vulnerable population of children who, with their families, face increased emotional, psychological, physical and

financial difficulties. Children with CCC form a subpopulation of children with special health care needs (McPherson et al., 1998), and are described as having a health condition expected to last at least 12 months that substantially affects one or more body systems. These conditions lead to the need for pediatric specialty care and hospitalization (Feudtner, Christakis, & Connell, 2000), resulting in high health care utilization rates and associated health care costs. For example, children with CCC have longer pediatric emergency department (ED) length of stay and higher hospital and pediatric intensive care unit (PICU) admission rates (O'Mahony et al., 2013). Health care utilization rates among children with CCC significantly increased between 1997 and 2006, and in 2006 hospitalizations among children with CCC accounted for 26% of pediatric inpatient days and 41% of pediatric hospital charges (Simon et al., 2010). Moreover, issues pertaining to location such as geographic proximity to health care, access to care, and availability of resources may influence health care utilization patterns among children with CCC (Pollack et al., 2004; Yamamoto et al., 1995).

Identifying place-related factors associated with health care utilization is critical since rural-dwelling children are more likely to have unmet health care needs, at least one ED visit within a year (DeVoe, Krois, & Stenger, 2009), higher asthma hospitalization rates (Knudson, Casey, Burlew, & Davidson, 2009), higher use of medical settings for dental needs (Martin, Vyavaharkar, Veschusio, & Kirby, 2012), and limited access to pediatric subspecialty providers (Mayer, 2008). Rural areas also see higher infant mortality rates and higher rates of obesity in children (Wright et al., 2008). Therefore, this study was designed to address the research question: What multi-level place-related

factors put children with CCC at risk for or protect them against hospital admissions or ED visits?

Theoretical Framework

The risk and protective factors model (Hawkins, Catalano, & Miller, 1992) and social ecological theory (SET) (Bronfenbrenner, 1994) served as the theoretical frameworks for this study. According to the risk and protective factors model, certain aspects of an individual or the environment lead to an increased likelihood of a particular outcome (risk factors) while other aspects are associated with a lesser likelihood of the outcome (protective factors) (Hawkins et al., 1992; Nagy & Fawcett, 2011). Risk factors have varying degrees of modifiability and some, such as race/ethnicity, are impossible to change. According to this model, protective factors mediate or moderate the effect of the risk factor on the outcome (Hawkins et al., 1992). In fact, among persons with similar risk factors, those with protective factors have improved outcomes. The domains of factors in this framework are: individual/peer, school, family, and community.

The risk and protective factors (RPF) model has been widely used to address drug use and other risk behaviors in adolescents and has guided the development of a community program for addressing adolescent health behavior (Hawkins et al., 2008). The model has also been used as the theoretical framework in studies investigating hospital readmission behaviors (Bachrach, Schwarz, & Bachrach, 2003; Bulkow, Singleton, Karron, Harrison, & the Alaska RSV Study Group, 2002; Garcia-Aymerich et al., 2000; Garcia-Aymerich et al., 2003; Garcia-Aymerich et al., 2004; Garcia-Aymerich et al., 2001; Guevara, Young, & Mueller, 2001). However, no study was identified in which the RPF model was used to investigate hospital admissions and ED visits in

children with CCC. In this study, aspects pertaining to place, such as rural residence and proximity to care, were assessed as risk or protective factors for hospital admissions or ED visits in infants and young children with CCC.

Social ecological theory was used in conjunction with the RPF model during the qualitative analysis in this study. According to SET, drivers of behavior exist on multiple levels: intrapersonal, interpersonal, family, community, society, and political. Additional tenets of SET posit that behavioral influences on each level interact and successful behavior change strategies address influences on multiple levels (Sallis, Owen, & Fisher, 2008). Interview and focus group questions were formulated using the key concepts of the RPF model and SET, and during data analysis, initial coding categories were created using the guiding frameworks. In addition, particular attention was paid during data analysis to quotes and phrases that indicated differences or disparities pertaining to place.

Methods

Design

A convergent parallel mixed methods study was conducted using simultaneous, independent quantitative and qualitative methods. The quantitative phase of the study was conducted using a retrospective cohort design with medical record review. During the qualitative phase of the study, key informant interviews with parents/primary caregivers (subsequently referred to as "parents") and focus groups with health care providers (HCPs) were conducted using qualitative descriptive design and analyzed using directed content analysis. While the purpose of the larger study was to investigate the risk and protective factors associated with hospital admissions and ED visits in children with CCC, the focus of this sub-study was to identify place-related factors associated with

hospital utilization in infants and young children with CCC. Findings from the larger study are presented elsewhere; this sub-study was conducted with a focus on the place-related variables and the place-related qualitative data. The primary objectives were to 1) investigate the role of urban versus rural residence on hospital utilization, 2) explore the perceptions of parents and HCPs regarding place-related factors associated with hospital utilization in children with CCC, and 3) organize issues pertaining to location into an ecological risk and protective factors model.

Setting. The study was conducted at a 453-bed level III trauma regional hospital that serves a 15-county area of South Carolina (McLeod Health, 2012) with more than 875,000 residents (United States Census Bureau [USCB], 2013). The hospital is the main provider of acute care pediatric services in the area, with a pediatric general care floor, a pediatric intensive care unit, and some pediatric specialty providers, such as pediatric intensivists and a pediatric cardiologist. There is no freestanding pediatric hospital in the region. This setting was ideal for assessing the possible effects of location on hospital admissions and ED visits because several community hospitals in surrounding rural counties transfer higher-needs patients to the urban hospital.

The US Office of Management and Budget's (OMB's) definition of rurality was adopted for this study. According to this definition, a metropolitan area has at least 50,000 residents, a micropolitan area has an urban center of at least 10,000 but not more than 50,000 residents, and a non-metropolitan area has fewer than 10,000 residents in a central area (USCB, n.d.). Micropolitan and non-metropolitan statistical areas are considered rural, while metropolitan statistical areas are considered urban. This study was conducted in an urban county primarily surrounded by rural counties.

Sample. Medical records of children with CCC born between January 1, 2008 and November 25, 2011 were reviewed. Records for children having an index hospitalization with a diagnosis on the list of complex chronic conditions outlined by Feudtner and colleagues (2000) along with at least one additional hospital admission or ED visit within 365 days were selected for further analysis. Additional details can be found in Hudson, Mueller et al. (2014a).

Any parent who was at least 18 years of age and was the caregiver of a child born between January 1, 2008 and November 25, 2011 with a diagnosis that met the definition of complex chronic condition (Feudtner et al., 2000) and at least one additional hospitalization or ED visit was recruited to participate in key informant interviews. HCPs working locally in pediatric acute care, pediatric primary care, or emergency care were recruited to participate in focus groups. Participating HCPs included physicians, nurses, ancillary care providers, and other disciplines; each HCP had worked for at least 1 year caring for children with CCC, and directly cared for children with CCC in their current role.

Data Collection. Data collection processes are presented in greater detail in the reports of the quantitative (Hudson, Mueller, et al., 2014a) and qualitative (Hudson, Newman, et al., 2014b) phases of the larger study. A hand search of the medical records was performed to identify a cohort of children with CCC born between January 1, 2008 and November 25, 2011 (n = 216). The demographic and clinical data collected included: age, sex, race/ethnicity, type of insurance, county of residence, zip code of residence, technological dependence, primary diagnosis for each admission, and number and type of secondary diagnoses for each admission. Measures of hospital admissions and ED visits

collected were: index (or initial) hospitalization admission date, index hospitalization discharge date, number of additional hospital admissions and/or ED visits, and dates for each subsequent hospitalization or ED visit.

Qualitative data collection was carried out using key informant interviews and focus groups. Questions specific to location such as perceptions of the roles of transportation, distance to health care providers, and community resources were included in the interview and focus group interview guides. The findings from interviews with parents and focus groups with HCPs were compared, as were findings from interviews with rural-dwelling and urban-dwelling parents. Institutional Review Board (IRB) approval was obtained from the study site and the principal investigator's (PI's) institution (Pro00016037) prior to data collection.

Data Analysis. Data accuracy was ensured by verifying data entry with the source document, and by checking for missing data and outliers. Descriptive statistics were calculated to assess the characteristics of rural-dwelling and urban-dwelling children with CCC. Linear regression analyses were conducted to examine whether associations were present between urban versus rural residence and measures of hospital utilization. Outcome variables were: length of stay (LOS) during the index hospitalization, number of hospital admissions and/or ED visits (occurrences) following the index hospitalization, number of days between the index hospitalization and the first subsequent hospital admission or ED visit, and mean number of days between all subsequent hospital admissions and/or ED visits. After bivariate analyses between urban versus rural residence and each outcome variable, multiple regression analyses were conducted to determine whether the addition of urban versus rural residence influenced the relationship

with predictors and outcome measures. Multiple regression analyses were conducted with the set of demographic and clinical variables with and without the residence variable as possible predictors of the outcome variables to evaluate differences. Stepwise linear regression modeling with backward deletion was performed with the level of significance for variable entry set at $p < .10$, and the level of significance for variable removal set at $p > .15$ to reduce the probability of a type II error.

Qualitative data were analyzed using directed content analysis (Hsieh & Shannon, 2005) guided by an ecological risk and protective factors framework. To begin the analysis, initial coding categories were chosen using the ecological risk and protective factors framework that emerged during the qualitative phase of the larger study (Hudson, Newman, et al., 2014b). Quotes that seemed to fit into a category were highlighted on the interview or focus group transcript. Transcripts were reviewed again, and highlighted segments were coded into one or more categories. Phrases associated with place, location, or residence were sought. Lincoln and Guba's (1985) framework for developing trustworthiness was adopted to enhance the quality of this portion of the study. The PI kept a field journal and recorded personal influences to promote reflexivity. Subject checking was conducted to verify findings.

Results

Demographic and clinical characteristics of rural- versus urban-dwelling children from the medical record review (n = 216) are presented in Table 1. Urban-dwelling and rural-dwelling groups differed in hospital utilization. Rural-dwelling children had a significantly longer average index hospitalization LOS than urban-dwelling children but

statistically significantly fewer occurrences following the index hospitalization.

Characteristics of hospital utilization by residence are outlined in Table 2.

Table 1

Medical Record Sample Demographic and Clinical Data by Urban versus Rural Status

Variable	Urban N = 144 Proportion (n) or Mean $\pm$ SD (Range)	Rural N = 70 Proportion (n) or Mean $\pm$ SD (Range)	*p*-value
Age			
Age (in months)	31.5 $\pm$ 13.1 (7.0- 52.0)	31.9 $\pm$ 13.8 (6.0- 52.0)	.72
Gender			
Male	48.6 (70)	52.9 (37)	.56
Female	51.4 (74)	47.1 (33)	.56
Race/ethnicity			
White	31.9 (46)	42.9 (30)	.12
Black	63.9 (92)	50.0 (35)	.05
Asian/Pacific Islander	0.7 (1)	0	.49
Native American/Alaskan Native	0	2.9 (2)	.04
Hispanic or Spanish origin	2.1 (3)	2.9 (2)	.73
Other	1.4 (2)	1.4 (1)	.98
Procedures			
None	79.2 (114)	77.1 (54)	.74
Tracheostomy	2.8 (4)	2.9 (2)	.97
Gastrostomy	14.6 (21)	15.7 (11)	.83
Permanent indwelling catheter	2.1 (3)	1.4 (1)	.74
Ventriculoperitoneal shunt	5.6 (8)	7.1 (5)	.65
Index admission primary diagnosis category			
Neuromuscular	6.3 (9)	5.7 (4)	.88
Cardiovascular	1.4 (2)	2.9 (2)	.46
Respiratory	11.1 (16)	15.7 (11)	.34
Renal	0	1.4 (1)	.15
Hematological/ Immunological	2.1 (3)	1.4 (1)	.74
Metabolic	0	4.3 (3)	.01
Perinatal/birth	72.0 (105)	67.1 (47)	.38
Other	6.3 (9)	1.4 (1)	.12
Index hospitalization number of secondary diagnoses	6.4 $\pm$ 5.4 (0- 29) Median = 5.0	7.5 $\pm$ 5.9 (0- 21) Median = 7.0	.27
Per patient mean number of secondary diagnoses (subsequent events)	1.0 $\pm$ 1.5 (0- 13.5) Median = 0.6	1.2 $\pm$ 1.4 (0- 8) Median = 1.0	.16

	Insurance		
Public	88.2 (127)	91.4 (64)	.47
Private	15.3 (22)	14.3 (10)	.85
Self-pay	2.8 (4)	1.4 (1)	.54
	Number of types of insurance		
One type (or self-pay)	93.8 (135)	92.9 (65)	.80
Two types	6.3 (9)	7.1 (5)	.80
	Family status		
	(n = 103)	(n = 49)	
Single-parent	46.6 (48)	46.9 (23)	.95
Two-parent	48.5 (50)	49.0 (24)	.95
Other relative	2.9 (3)	4.1 (2)	.73
Other non-relative	1.9 (2)	0	.32
Number of siblings	(n = 95)	(n = 47)	.74
	1.3 ± 1.4 (0- 9)	1.6 ± 1.9 (0- 7)	

The parents of 11 children expressed interest in participating, and the parent(s) of 8 children (n = 13) were enrolled in the study; 27 HCPs provided informed consent, and 24 participated in focus groups. The demographic profiles of parents and HCPs are presented in Hudson, Newman, et al. (2014b). The majority of parents resided in an urban county (84.6%, 11/13); however, 36.3% (4/11) of these parents described living in more sparsely populated areas of the county. Characteristics of hospital utilization by residence are outlined in Table 2.

Table 2

Hospital Admissions and ED Visits by Urban versus Rural Status

Variable	Urban N = 144 Proportion (n), or Mean + SD (Range)	Rural N = 70 Proportion (n), or Mean + SD (Range)	p-value
Number of occurrences following index hospitalization	3.1 + 2.8 (1-16) Median = 2.0	2.2 + 1.9 (1-8) Median = 1.5	.02
Number of days between index hospitalization discharge and first subsequent occurrence	N = 144 115.2 + 100.0 (1-357) Median = 75.0	N = 70 106.9 + 98.7 (1-356) Median = 73.0	.48
Per patient mean number of	N = 90	N = 31	.68

days between subsequent occurrences	108.1 + 81.5 (.5-330.0) Median = 94.0	117.6 + 87.1 (5.0-308.0) Median = 88.2	
Index hospitalization LOS in days	22.4 + 31.3 (0-117) Median = 4.0	37.2 + 43.5 (1-194) Median = 14.0	.003

Merged findings by ecological level

Qualitative and quantitative findings were merged using side-by-side analysis for convergence and divergence. Merged findings are presented as follows by ecological level.

Individual child. Parents and HCPs perceived that the complexity and severity of the child's condition influenced the location of care. Parents also perceived that the complexity of their child's condition mandated they bring their child to a particular ED or hospital. A father described one of the reasons he chose to bring his daughter to a preferred urban hospital: "I don't think at [hospital name], I don't think they have a special floor for pediatrics and taking care of a baby that has [a CCC]." Results from multiple regression analyses supported these beliefs. Reliance on a technological device (such as a tracheostomy or gastrostomy tube) was included in the prediction models for the number of occurrences that followed the index admission (R^2 = .28, $F(9, 203)$ = 8.56, $P < .001$) (Table 3), the number of days between the index admission and the first subsequent occurrence ($R^2 = .10$, $F(5, 207) = 4.47$, $P = .001$) (Table 4), and the mean number of days between occurrences that followed the index admission ($R^2 = .16$, $F(5, 122) = 4.58$, $P = .001$) (Table 5).

Table 3

Coefficients for the Final Model for Predictors of the Number of Occurrences Following the Index Hospitalization

Predictor	B	Std. error	t	p	Bivariate r	Partial r
Constant	3.556	0.687	5.173	.022		
Rural versus urban	-0.932	0.329	-2.834	.005	-.158	-.195
Other race/ethnicity	-1.169	0.707	-1.655	.100	-.088	-.115
Neurological diagnosis	1.358	0.659	2.061	.041	.152	.143
Cardiovascular diagnosis	2.824	1.130	2.498	.013	.134	.173
Other diagnosis	-1.119	0.731	-1.530	.128	-.060	-.107
Age in months	0.057	0.012	4.913	<.001	.340	.326
No technological device	-1.598	0.380	-4.201	<.001	-.269	-.283
Private insurance	-0.918	0.431	-2.131	.034	-.114	-.148
Self-pay	1.646	1.015	1.621	.107	.098	.113

Table 4

Coefficients for the Final Model for Predictors of the Number of Days between the Index

Hospitalization and the First Subsequent Occurrence

Predictor	B	Std. error	t	P	Bivariate r	Partial r
Constant	93.327	24.932	3.743	<.001		
Rural versus urban	-6.422	14.020	-0.458	.647	-.037	-.032
Hematology/Immunology diagnosis	-104.215	48.202	-2.162	.032	-.122	-.149
Mean number of secondary diagnoses during subsequent occurrences	-51.325	30.338	-1.692	.092	-.152	-.117
No technological device	55.753	16.435	3.392	.001	.238	.229
Self-pay	-66.854	43.674	-1.531	.127	-.062	-.106

Table 5

Coefficients for the Final Model for Predictors of the Mean Number of Days between

Subsequent Occurrences

Predictor	B	Std. error	t	p	Bivariate r	Partial r
Constant	91.780	73.582	1.247	.215		

Rural versus urban	45.871	27.586	1.663	.099	.091	.149
Mean number of secondary diagnoses during subsequent occurrences	-135.387	68.912	-1.965	.052	-.203	-.175
Age in months	2.443	1.004	2.443	.016	.179	.215
No technological device	54.642	30.493	1.792	.076	.182	.160
Public insurance	-91.586	40.045	-2.287	.024	-.225	-.203

Thus, children with CCC severe enough to require a technological device had more hospital admissions or ED visits (occurrences) and fewer days between occurrences. Number of secondary diagnoses was statistically significant in the prediction models for the number of days between occurrences following the index admission and for the index admission LOS (R^2 = .73, F (5, 207) = 113.56, P < .001) (Table 6). These results further supported parents' and HCPs' beliefs by indicating children with a higher number of secondary diagnoses during hospitalizations had fewer days between occurrences and a longer index hospitalization LOS than those with fewer secondary diagnoses.

Parent-child relationship. Parents and HCPs frequently mentioned the influence of parents' preferences on location of care. According to HCPs, this preference can place children at risk for greater utilization because parents spend time driving from distant locations during which the child's condition deteriorates. But parents believed spending the extra time driving to a preferred hospital protected children because urban centers have needed equipment and personnel with expertise.

Table 6

Coefficients for the Final Model for Predictors of the Index Hospitalization Length of Stay

Predictor	B	Std. error	t	p	Bivariate r	Partial r
Constant	-31.760	5.844	-5.435	<.001		
Rural versus urban	6.137	2.653	2.313	.022	.169	.159
No technological device	5.754	3.138	1.834	.068	-.108	.126
Neurological diagnosis	9.661	5.420	1.783	.076	-.153	.123
Number of index hospitalization secondary diagnoses	5.625	0.248	22.663	<.001	.842	.844
Age in months	0.247	0.094	2.632	.009	.056	.180

One mother described how she decides whether to travel to a more distant urban center:

> *When I'm in the car with her, I'm, like, 'Can I make it? Do I need to go to [the rural ED]?' I think if it came to the point where I thought, okay, this is enough and I was by [the rural hospital] she would go to [the rural hospital]. So I just feel, I guess, comfortable enough to drive the extra 20 minutes and get to where I know she'll be seen immediately and get taken care of.*

Many times, parents' decisions are influenced by their knowledge and experience with taking their child with CCC to particular hospitals. One mother said that because her child's condition is severe she is taken "immediately back [to be seen], no matter what. Soon as I walk in [to preferred hospital's name], we are back…we don't even sign in. We go automatically back." Because she does not want her child to wait to be seen, the mother always brings her child to this ED.

Parents' access to care and ability to choose a particular hospital is influenced by their available resources. Those who have transportation describe weighing the severity

of the child's condition against the time needed to drive to the preferred hospital, whereas the decisions of those without readily available transportation are determined by the proximity of care. Parents who lived in close proximity to an ED said they took their children to the ED when they didn't have the resources, such as a vehicle or bus fare, to take them to see their primary care provider (PCP) across town. Similarly, parents stated lacking money or gas influenced their decisions and access to care. A rural-dwelling mother discussed the problems she faced with her husband working out-of-town and her lack of a telephone: "I get worried sometimes because…what if she has a seizure and I can't get up with my husband. If she has a seizure, do I just let her lay there? Is she gonna die or snap to?"

Parents' level of comfort with managing the child's condition was another influence on location of health care. Parents and HCPs described situations during which parents tried to manage the child's condition at home before bringing the child to be seen. HCPs believed rural-dwelling parents attempted to manage the child's condition longer than urban-dwelling parents because of the challenges associated with having a child hospitalized far from home. According to one HCP, rural-dwelling parents "know that if my kid really is sick enough to be in the hospital then I'm going to have a problem with my other kids; I'm going to have a problem with my job."

Multiple regression analyses of medical record data supported the position that lack of resources is associated with increased hospital utilization. Public insurance and/or self-pay status were statistically significantly associated with higher hospital utilization (ie, more occurrences and fewer days between occurrences). Public insurance was considered a proxy for lack of resources. Although Medicaid standards vary by state,

child eligibility is based on parents' income (Centers for Medicare and Medicaid Services, n.d.).

Family relationships and structure. Parents and HCPs perceived that the proximity of extended family and friends and their availability to provide support influenced location of health care. HCPs believed extended family members were essential sources of transportation and influenced parents' decisions regarding place of care. In addition to providing transportation to parents, extended family members watched siblings so that parents could take children with CCC to out-of-town specialists' appointments. Parents who had available extended family described the importance of this resource while parents who did not have friends or family near expressed frustration with the lack of this resource.

Heath care provider relationships. Parents and HCPs frequently mentioned factors pertaining to health care relationships. Both rural- and urban-dwelling parents described choosing to take their child to a hospital farther from home because of their personal preferences. One father described the reasons he preferred a particular hospital: "It makes me feel more comfortable…it's more of a home setting, the doctor's more friendly." Relationships with HCPs were built on previous experiences and were also influenced by the interactions the parents observed between the staff and the child. The parents of a child with frequent hospitalizations said the following: "Since we've been up here, like we got to know the nurses, the nurses got to know us, so its […] more comfortable. You feel more comfortable, and I guess [the child] feels more comfortable because of the familiar faces." HCPs agreed that familiarity with a child was beneficial. According to one HCP, a lack of familiarity "puts you even further behind [in the child's

care] because you know this child has something, and you just don't know what it is."
Beyond being familiar with individual children, staff's expertise with caring for children
with CCC in general was a perceived benefit. One HCP described the effect of rural
staff's familiarity with children with CCC:

> ...sometimes the comfort level of the physician and the staff, the more complex a
> child is, they're very uncomfortable or they may not do everything to begin with
> that they need to do, and that child continues to deteriorate in the emergency room
> before they make a phone call [to a more urban hospital].

Parents described a lack of satisfaction with some rural hospitals because they
believed staff "couldn't handle" or "didn't understand" the child's condition. Parents
preferred staff members who not only "knew how to handle [the child's condition] and
knew all the medicines to give her" but also interacted with the child through talk and
play.

Parents and HCPs believed communication was a factor that influenced health care
utilization. According to HCPs, effective communication between providers at smaller
community hospitals and those at centers capable of providing a higher level of care was
essential to optimal care delivery for children with highly complex conditions. Through
effective communication, HCPs in rural areas could discuss conditions with HCPs in
centers providing higher levels of care who also may be more familiar with the conditions
as well as with individual children with CCC. Parents also valued effective
communication with PCPs and were willing to travel an hour or more to find a PCP who
"is really listening and valuing what I have to say and taking that into consideration to
make the right judgment call for my kids."

Health care system environment. Parents' familiarity with the processes at a particular hospital influenced utilization. Parents described knowing, for instance, that the wait time at an ED would be longer and deciding to visit another hospital's ED instead. However, in the case of an emergency, parents abandoned their preferences for a particular location and instead took the child to the nearest hospital. Parents perceived, and HCPs agreed, that some locations lacked equipment or expertise to adequately treat a child with CCC. One mother relayed her perception of this lack of expertise:

Basically, I went to the ER with her one morning and he [the physician] told me, 'Oh well, you shouldn't put her through more than what she has to go through, she's already sick enough, don't keep running up here every time you feel like something's wrong.' So that was the last time I went to [hospital] because something actually was wrong. Because we came here [preferred hospital] and she got admitted.

Parents believed some hospitals lacked trained staff able to care for children with CCC. The lack of local specialists and other health care services needed by children with CCC meant that all parents, including those who reported urban residence, faced access to care issues and were required to travel an hour or more for care. Parents also believed the stress of traveling out of town to see specialists would be relieved by the availability of local clinics or home visits. The lack of health personnel in rural locations also included out-of-hospital services. According to one mother, in her community emergency medical service (EMS) providers are not located at a central station so ambulances could take an hour to reach the child. When the child had a seizure, the parents "had to go to the EMS station" to receive timely treatment.

Community environment. Parents and HCPs perceived that a lack of community resources and organizations influenced rural health care utilization. One HCP argued that an absence of resources in rural locations could substantially affect care:

The more rural (further out they are), the less resources are available to go out there because there are some places that only have physical therapy that cover this area. So you could be in a spot and have a really chronic child and have no resources available to you because you live there.

HCPs believed identifying a PCP in each community who was comfortable with caring for children with CCC would benefit these children. Parents did not discuss a lack of health care organizations in rural areas, and instead mentioned the lack of community groups. One mother knew of a parents' support group in a more metropolitan area, but not of a local group. She attested to location-associated limitations when she said, "I can't go three hours, two and a half hours away every time I feel like I need to have a support group." Rural versus urban residence was statistically significant in the prediction models for index admission LOS, number of occurrences, and mean number of days between occurrences that followed the index admission. Rural residence was associated with fewer occurrences and more days between occurrences. This finding seems to refute parents' and HCPs' beliefs; however, rural residence was associated with a longer index hospitalization LOS.

Discussion

The findings led to an ecological model of place-related risk and protective factors for hospital admissions and ED visits among children with CCC (Figure 1). Hospital utilization differed between rural- and urban-dwelling children with CCC.

Increased complexity, or severity of the child's condition, was the only biological risk factor associated with hospital utilization identified in this study. Despite participants' perceptions that increased complexity led to the need for care at urban centers, rural residence was associated with fewer hospital admissions and ED visits and more days between hospitalizations and visits. This finding may result from data being collected solely at one urban hospital.

All parent participants reported using other urban or rural hospitals, thus findings from the medical record review most likely underestimate true utilization rates. While rural residence was in some cases associated with lower rates of utilization, it was also associated with a longer index hospitalization LOS. This finding may suggest rural-dwelling children are sicker on transfer to an urban center, or may suggest more time is needed for rural-dwelling parents to prepare the home environment for children with CCC prior to hospital discharge. Park and colleagues found that rural-dwelling children with liver transplant did not have significantly poorer health outcomes, but tended to be sicker at the time of transplantation than urban-dwelling children (Park et al., 2011).

The lower rates of hospitalizations or ED visits and higher number of days between hospitalizations or visits may also indicate disparities in access to care among rural-dwelling children. Access disparities have been discovered between low-income rural- and urban- dwelling children (DeVoe et al., 2009). According to Laditka and colleagues (2009), rural-dwelling children are more likely to be hospitalized for ambulatory care sensitive conditions, findings which suggest disparities in access to primary care. Similarly, Roy, McGinty, Hayes, and Zhang (2010) report rural-dwelling children with

chronic illness have higher rates of hospitalization than urban-dwelling children that may be related to environmental, social, or access to care issues.

Many of the parents in this study resided in an urban county, but nearly all of these parents discussed place-specific issues such as utilization of rural hospital services, choice of one urban hospital over another, or travel to a more metropolitan area for specialty services. Although this study was conducted at a hospital in an urban county, many pediatric specialty providers are located in the largest metropolitan areas of South Carolina, approximately 80 to 130 miles away. The lack of local specialty providers corresponds with Mayer's (2008) findings that rural and smaller metropolitan areas had poorer geographic access to pediatric specialty providers. The finding that place-related issues were prevalent among both urban- and rural-dwelling participants suggests access-to-care issues are faced not only by the most rural-dwelling children but also by children with complex chronic conditions in smaller metropolitan areas.

When considered in conjunction with the Rural Nursing theory (Long & Weinert, 1989), findings from this study have particular relevance for nurses in rural-dwelling areas. For instance, according to Rural Nursing theory, rural-dwelling people equate work with health and are often viewed as postponing health care until the illness has advanced to the point of requiring hospitalization. Findings from this study support this statement and may suggest that nurses and primary care providers be more easily accessible to rural-dwelling children with CCC. However, Rural Nursing Theory also posits that rural nurses and other rural HCPs may need to have extended time with communities to gain acceptance and trust, which can affect access if no established providers are available. This study suggests that parents and caregivers of children with CCC seek providers with

whom they have an established, trusting relationship. When viewed through the lens of Rural Nursing theory, this need for a trusting relationship may be more critical for rural-dwelling children with CCC and their families.

Limitations

Many of the parents who reported living in an urban county also reported using small community hospital services. This finding suggests that classifying rural versus urban residence by county may not accurately reflect rural versus urban utilization. Another limitation results from data having been collected only at one urban hospital. Nearly all of the interview participants described using other hospitals or EDs indicating an underestimation of hospital utilization in the quantitative portion of the study. This limitation may also affect the relationships between rural versus urban status and hospital utilization found in this study. Another limitation was that qualitative findings indicated additional quantitative variables should have been collected. For instance, no quantitative variables on the health care provider relationships level were available to compare with qualitative findings.

<div align="center">

Conclusion

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The results from this study reveal differences in hospital utilization between rural- and urban-dwelling children with CCC. The findings provide evidence of access issues and extend the problem beyond rural counties to urban counties with rural communities and smaller metropolitan areas. Further study is needed to develop a more comprehensive understanding of patterns of hospital utilization among rural-dwelling children with CCC to include admissions and ED visits at rural and urban hospitals, primary care utilization, and outpatient services utilization. Knowledge gained from further study can support and

build upon the risk and protective factors model developed in this study and interventions can be designed to minimize risk factors and strengthen protective factors for hospital admissions and ED visits among children with CCC.

References

Bachrach, Virginia R. Galton, Schwarz, Eleanor, & Bachrach, Lela Rose. (2003). Breastfeeding and the risk of hospitalization for respiratory disease in infancy: A meta-analysis. *Archives of Pediatric and Adolescent Medicine, 157*(3), 237-243. http://dx.doi.org/10.1001/archpedi .157.3.237

Bronfenbrenner, U. (1994). Ecological models of human development. International Encyclopedia of Education (2nd ed., Vol. 3). Oxford: Elsevier.

Bulkow, Lisa R., Singleton, Rosalyn J., Karron, Ruth A., Harrison, Lee H., & the Alaska RSV Study Group. (2002). Risk factors for severe respiratory syncytial virus infection among Alaska Native children. *Pediatrics, 109*(2), 210-216. http://dx.doi.org/10.1542/peds. 109.2.210

Centers for Medicare and Medicaid Services. (n.d.). InsureKidsNow.gov: connecting kids to coverage. Retrieved from http://www.insurekidsnow.gov/chip/index.html

DeVoe, J. E., Krois, L., & Stenger, R. (2009). Do children in rural areas still have different access to health care? Results from a statewide survey of Oregon's food stamp population. *Journal of Rural Health, 25*(1), 1-7. http://dx.doi.org/10.1111/j.1748-0361.2009.00192.x

Feudtner, C., Christakis, D. A., & Connell, F. A. (2000). Pediatric deaths attributable to complex chronic conditions: A population-based study of Washington State, 1980-1997. *Pediatrics, 106*(1), 205-209. http://dx.doi/org/10.1542/peds.106.1.S1.205

Garcia-Aymerich, J., Barreiro, E., Farrero, E., Marrades, R. M., Morera, J., & Anto, J. M. (2000). Patients hospitalized for COPD have a high prevalence of modifiable risk factors for exacerbation (EFRAM study). *European Respiratory Journal, 16*, 1037-1042. http://dx.doi.org/10.1034/j.1399-3003.2000.16f03.x

Garcia-Aymerich, J., Farrero, E., Felez, M. A., Izquierdo, J., Marrades, R. M., & Anto, J. M. (2003). Risk factors of readmission to hospital for a COPD exacerbation: A prospective study. *Thorax, 58*, 100-105. http://dx.doi.org/10.1136/thorax.58.2.100

Garcia-Aymerich, J., Marrades, R. M., Monso, E., Barreiro, E., Farrero, E., & Anto, J. M. (2004). Paradoxical results in the study of risk factors of chronic obstructive pulmonary disease (COPD) re-admission. *Respiratory Medicine, 98*(9), 851-857. http://dx.doi.org/10.1016/j.rmed.2004.02.019

Garcia-Aymerich, J., Monso, E., Marrades, R. M., Escarrabill, J., Felez, M. A., Sunyer, J., . . . Efram Investigators. (2001). Risk factors for hospitalization for a chronic obstructive pulmonary disease exacerbation. *American Journal of Respiratory and Critical Care Medicine, 164*(6), 1002-1007. http://dx.doi.org/10.1164/ajrccm.164.6.2006012

Guevara, J. P., Young, J. C. C., & Mueller, B. A. . (2001). Do protective factors reduce the risk of hospitalization in infants of teenaged mothers? *Archives of Pediatric and Adolescent Medicine, 155*, 66-72. http://dx.doi.org/10.1001/archpedi.155.1.66

Hawkins, J. D., Brown, E. C., Oesterle, S., Arthur, M. W., Abbott, R. D., & Catalano, R. F. (2008). Early effects of Communities That Care on targeted risks and initiation of delinquent behavior and substance use. *Journal of Adolescent Health, 43*, 15-22. http://dx.doi.org/10.1016/j.jadohealth.2008.01.022

Hawkins, J. D., Catalano, R. F., & Miller, J. Y. (1992). Risk and protective factors for alcohol and other drug problems in adolescence and early adulthood: implications for substance abuse prevention. *American Psychological Bulletin, 112*(1), 64-105. http://dx.doi.org/10.1037/0033-2909.112.1.64

Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. http://dx.doi.org/10.1177/1049732305276687

Hudson, S.M., Mueller, M., Hester, W. H., Magwood, G.S., Newman, S.D., & Laken, M.A. (2014a). At-risk characteristics for hospital admissions and ED visits. *Journal for Specialists in Pediatric Nursing, 19*, 183-193. http://dx.doi.org/10.1111/jspn/12068

Hudson, S.M., Newman, S.D., Hester, W.H., Magwood, G.S., Mueller, M., & Laken, M.A. (2014b). Factors influencing hospital admissions and emergency department visits among children with complex chronic conditions: a qualitative study of parents' and providers' perspectives. *Issues in Comprehensive Pediatric Nursing, 37*(1), 61-80. http://dx.doi.org/10.3109/01460862.2013.855844

Knudson, A., Casey, M., Burlew, M., & Davidson, G. (2009). Disparities in pediatric asthma hospitalizations. *Journal of Public Health Management Practice, 15*(3), 232-237. http://dx.doi.org/10.1097/01.PHH.0000349739.81243.ea

Laditka, J. N., Laditka, S. B., & Probst, J. C. (2009). Health care access in rural areas: evidence that hospitalization for ambulatory care-sensitive conditions in the United States may increase with the level of rurality. *Health & Place, 15*(3), 761-770. http://dx.doi.org/10.1016/j.healthplace.2008.12.007

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage Publications, Inc.

Long, K. A. , & Weinert, C. (1989). Rural nursing: Developing the theory base. *Scholarly Inquiry for Nursing Practice, 3*(2), 113-127.

Martin, A. B., Vyavaharkar, M., Veschusio, C., & Kirby, H. (2012). Rural-urban differences in dental service utilization among an early childhood population enrolled in South Carolina Medicaid. *Maternal Child Health Journal, 16*, 203-211. http://dx.doi.org/10.1007/s10995-010-0725-1

Mayer, M. L. (2008). Disparities in geographic access to pediatric subspecialty care. *Maternal Child Health Journal, 12*, 624-632. http://dx.doi.org/10.1007/s10995-007-0275-3

McLeod Health. (2012). Physician recruitment FAQ's. Retrieved from http://www.mcleodhealth.org/MRMC/physician_faq.cfm

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., . . . Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics, 102*(1), 137-139. http://dx.doi.org/10.1542/peds.102.1.137

Nagy, J., & Fawcett, S. B. (2011). Understanding risk and protective factors: Their use in

    selecting potential targets and promising strategies for interventions. The

    Community Toolbox. Retrieved from

    http://ctb.ku.edu/en/tablecontents/sub_section_main_1156.aspx

O'Mahony, L., O'Mahony, D. S., Simon, T. D., Neff, J., Klein, E. J., & Quan, L. (2013).

    Medical complexity and pediatric emergency department and inpatient utilization.

    Pediatrics, 131(2), e559-565. http://dx.doi.org/10.1542/peds.2012-1455

Park, K. T., Nanda, P., Bensen, R., Strichartz, D., Esquivel, C., & Cox, K. (2011). Effects

    of rural status on health outcomes in pediatric liver transplantation: a single center

    analysis of 388 patients. *Pediatric Transplantation, 15*, 300-305.

    http://dx.doi.org/10.1111/j.1399-3046.2010.01452.x

Pollack, H. A., Dombkowski, K. J., Zimmerman, J. B., Davis, M. M., Cowan, A. E.,

    Wheeler, J. R., . . . Freed, G. L. (2004). Emergency department use among

    Michigan children with special health care needs: an introductory study. *Health*

    Services Research, 39(3), 665-692. http://dx.doi.org/10.1111/j.1475-

    6773.2004.00250.x

Roy, S. R. , McGinty, E. E., Hayes, S. C. , & Zhang, L. (2010). Regional and racial

    disparities in asthma hospitalizations in Mississippi. *Journal of Allergy and Clinical*

    Immunology, 125(3), 636-642. http://dx.doi.org/10.1016/j.jaci.2009.11.046

Sallis, J. F., Owen, N., & Fisher, E. B. (2008). Ecological models of health behavior. In

    K. Glanz, B. K. Rimer & K. Viswanath (Eds.), Health behavior and health

    education (4th ed., pp. 465-485). San Francisco, CA: Jossey-Bass.

Simon, T. D., Berry, J. G., Feudtner, C. , Stone, B. L., Sheng, X., & Bratton, S. L. (2010). Children with complex chronic conditions in hinpatient hospital settings in the United States. Pediatrics, 126(4), 647-655. http://dx.doi.org/10.1542/peds.2009-3266

United States Census Bureau. (2013, June 11, 2014). State & county quick facts. Retrieved from http://quickfacts.census.gov/qfd/states/45000.html

United States Census Bureau. (n.d.). Metropolitan and micropolitan. Retrieved from http://www.census.gov/population/metro/

Wright, B., Bellinger, J. , Brahmbhatt, M. Y., Brokks, K. , Gangadaram, M. K., Garner, D. Q., . . . Wilkes, J. (2008). State rural plan for South Carolina. Columbia, SC: South Carolina Rural Health Research Center.

Yamamoto, L. G., Zimmerman, K. R., Butts, R. J. , Anaya, C. , Lee, P. , Miller, N. C. , . . . Leung, Y. (1995). Characteristics of frequent pediatric emergency department users. *Pediatric Emergency Care, 11*(6), 340-346. http://dx.doi.org/10.1097/00006565-199512000-00003