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Factors Influencing Hospital Admissions and Emergency Department Visits Among Children with Complex Chronic Conditions: A Qualitative Study of Parents' and Providers' Perspectives

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Abstract

Children with complex chronic conditions (CCC) have greater health care needs and use rates than children in general. Elevated health care use includes more frequent hospital admissions, longer hospital stays, and greater health care expenses. Prior studies have examined population characteristics associated with increased hospital admissions, emergency department (ED) use, and general healthcare use, yet few studies have investigated these events from the parents' or health care providers' point of view. The purpose of this study was to explore parents/caregivers' and health care providers' perceptions of the factors placing infants and young children with CCC at risk for or protecting them against hospital admissions and ED visits. Parents or primary caregivers participated in interviews, and health care providers in pediatric acute care, pediatric primary care, and emergency care participated in focus groups. Interview and focus group data were analyzed using directed content analysis and an ecological risk and protective factors model. The analysis revealed that parents/caregivers and health care providers described risk factors and protective factors on multiple ecological levels surrounding the child with CCC. This article presents these findings, which add to current knowledge of factors influencing hospital admissions and ED visits and may be used to inform interventions addressing high health care utilization in this population. This article concludes with the implications of the findings for future research and nursing practice.

Keywords

Child; chronic; disease; health personnel; patient readmission

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Introduction

Children with special health care needs (CSHCN) have substantially increased risk for emotional, developmental, or physical conditions that lead to greater health care needs than children in general (McPherson et al., 1998). Children with complex chronic conditions (CCC), a subset of CSHCN, have health conditions that are expected to last at least 12 months and affect multiple body systems or one system severely enough that specialty care and hospitalization are necessary (Feudtner et al., 2000). Children with CCC are a small population, accounting for only 3.2% of CSHCN and 0.4% of all children (Kuo et al., 2011), yet children with CCC have a significant impact on the health care system.

As a population, children with CCC in the US experience increased hospital admissions, inpatient days, associated hospital charges, and cost of care (Burns et al., 2010; Simon et al., 2010). Dependence on technology, such as gastrostomies, tracheostomies, and mechanical ventilation, increases Medicaid claims to approximately \$69,906 per year as compared to \$3,159 per year for well children (Buescher et al., 2006). High costs of health care utilization among children with CCC extend beyond Medicaid expenditures to expenses borne by families. Parents/caregivers of children with CCC have greater out-of-pocket expenditures (Kuo et al., 2011), greater difficulty maintaining steady employment (Kuo et al., 2011; Looman et al., 2009; Nageswaran et al., 2008), and greater need for additional income (Nageswaran et al., 2008) than parents/caregivers of children without chronic illnesses. Similar to findings in the US, children with CCC in other developed countries had higher rates of health care utilization than children without chronic conditions. Children with chronic conditions in the UK are at substantially increased risk of hospitalization for H1N1 influenza (Campbell et al., 2011) and in Australia, children with CCC accounted for a large proportion of children who visited the ED 20 or more times per year (Gibson et al., 2010). In Belgium, children with CCC had significantly more ED visits resulting in hospital or pediatric intensive care admissions than children without chronic conditions (Massin et al., 2006).

The effect of high health care utilization on children with CCC, their families, and the health care system necessitates further examination into the underlying causes of this high utilization. Few studies have investigated parents/caregivers' and health care providers' perceptions of factors contributing to hospital readmissions and repeat emergency department (ED) visits in children with CCC (Hudson, 2013). To address this knowledge gap, this study was guided by the research question: What are the perceptions of parents/primary caregivers (subsequently referred to as "parents") and healthcare providers (HCPs) regarding the risk and protective factors that contribute to hospital admissions and ED visits among children with CCC?

Methods

Theoretical Framework

An ecological risk and protective factors model guided this investigation of the multiple underlying factors associated with increased hospital admissions and ED visits among children with CCC. Bronfenbrenner (1994) proposed a social ecological model of human

development in which multiple levels of influence surround the individual including the family, peer groups, school, work, culture, and society. The core concepts of social ecological theory (SET) acknowledge that factors at multiple, interacting levels of the social ecology influence human behavior (Sallis et al., 2008). Interventions targeting multiple influencing factors at the personal and environmental levels in persons with chronic illness have been more successful in promoting change and positive health outcomes than those solely targeting individual behavior (Sallis et al., 2008; Stokols, 1996)

Accordingly, risk and protective factors are present across multiple ecological domains (Hawkins et al., 1992). *Risk factors* are the features of an individual or environment that are associated with an increased likelihood of a particular undesirable outcome while *protective factors* are those features associated with a lesser likelihood of a particular undesirable outcome (Nagy & Fawcett, 2011). Protective factors mediate or moderate the influence of risk factors on a specific outcome; therefore, for people with similar risk factors, those who also have protective factors are more likely to have improved outcomes.

Qualitative Approach

This study used a descriptive qualitative approach, through interviews with parents and focus groups with three groups of HCPs from pediatric acute care, emergency care, and pediatric primary care settings, to explore perceived risk and protective factors that contribute to hospital admissions and ED visits among children with CCC. Interviews and focus group sessions were transcribed, and analyses of these transcripts and field notes were conducted using directed content analysis (Hsieh & Shannon, 2005) with an ecological risk and protective factors coding framework.

Setting

The setting for this study was a large regional hospital with over 100 pediatric inpatient beds, a pediatric intensive care unit, and a level III neonatal intensive care unit in Northeast South Carolina. Prior to the beginning of the study, approval was obtained from the Institutional Review Board (IRB) at the study site and at the principal investigator (PI)'s institution.

Sample

Participants in individual interviews were parents of children with CCC born between January 1, 2008 and November 25, 2011, with at least one diagnosis on the list of CCC developed by Feudtner et al. (2000), and one or more hospital admissions or ED visits after the initial hospitalization. Participants were required to be aged 18 or older, to speak English, and to be free of any cognitive impairment that interfered with the ability to participate in an interview. Convenience, typical case sampling was used to locate parents meeting the inclusion criteria.

Focus group participants included HCPs who were at least 18 years old, currently providing direct care to children with CCC, with at least 1 year of experience working with children with CCC. Volunteer sampling was used to locate focus group participants in: the pediatric inpatient area, the hospital's ED, and pediatric primary care.

Data Collection

Data were collected from parents and HCPs using semi-structured interview schedules and open-ended questions with prompts. Parents received a gift card at the conclusion of the interview, and HCPs were served lunch during the focus groups. At the end of each interview and focus group, the PI collected demographic data using standardized forms. All interviews and focus group sessions lasted approximately 45 minutes. The PI audio-recorded interviews and focus group sessions and kept field notes of non-verbal cues and interviewer thoughts.

Data Analysis

Audio recordings from focus groups and interviews were transcribed verbatim; the PI compared each text transcript to the original audio recording. Transcripts were analyzed using QSR International's NVivo9 software (QSR International Pty Ltd., 2010) and directed content analysis (Hsieh & Shannon, 2005) with an ecological risk and protective factors model as the coding framework. The coding framework was created using a hierarchical nodes system of risk and protective factors at each of the levels of the ecological model in NVivo9. Member checking was conducted to verify the accuracy of the findings and resulted in two minor revisions to the results.

Qualitative Rigor

Lincoln & Guba's (1985) framework for developing trustworthiness in qualitative inquiry includes four criteria: credibility, dependability, confirmability, and transferability. *Credibility* is the degree of confidence investigators have in the truthfulness of the data and analysis. The PI enhanced credibility by establishing rapport with participants and by having multiple participants. *Dependability* pertains to the constancy of findings over time and was achieved by scrutinizing accuracy of transcripts produced from audio files and by conducting member checking with participants. *Confirmability* reflects the equivalence between the data provided by independent participants as well as the absence of bias introduced by the investigator. The PI established confirmability by maintaining a reflexive field journal and reflexive notes, by leaving an audit trail, and by comparing findings with published reports. *Transferability* indicates the ability to apply findings with one group or setting to other groups or settings. The PI supported transferability by providing descriptions of the study setting and population.

Results

Sample

Parents of 8 children ($n = 13$) enrolled in the study. The majority were female (69.2%) and mothers (61.5%) of a child with CCC. Approximately 62% were Black. Parents' mean age was 27.1 years, and children's mean age was 1.3 years. None of the children had technological dependence, but according to parents' reports, two children (25%) had conditions affecting multiple systems. Parent and child demographic and clinical data are reported in Table 1.

Twenty-four HCPs participated in three focus groups. Providers were mostly female (91.7%), white (83.3%), registered nurses (70.8%), with an average of 15 years of experience working with children with CCC. The full demographic profile of HCP participants is presented in Table 2.

Ecological Model of Influencing Factors

The initial coding framework mirrored the ecological domains of the risk and protective factors model, but the levels of the ecological model of influencing factors evolved throughout coding and analysis. The final model centered on the innermost *individual child* level. Factors pertaining directly to the child such as his/her biology or personality were included in this level. The next level was *parent-child relationships*, which included factors pertaining to the parent-child relationship and parent-child interactions. *Family structure and resources* emerged as the next level and included factors pertaining to family composition, siblings, grandparents, or other extended family members as well as the resources available to families. Because of the nature of their illnesses, these children are in frequent contact with the health care system and the relationships among children, parents, and HCPs were frequently mentioned. For these reasons, the *health care provider relationships* and *health care system environment* categories developed. *Community environment* was the final ecological level that emerged from the data. This category included not only factors pertaining to the community but also those related to society, policy, and community environments such as school and daycare. Risk and protective factors perceived by parents and HCPs were identified at each level of the ecological model (Table 3).

Individual Child

Risk Factors—Parents and HCPs perceived that the severity and complexity of the child's condition were key risk factors. Parents reported feeling the complexity of their child's illness and the speed of illness progression often forced the decision to go immediately to the ED to seek treatment. Further, parents believed their children were more susceptible to illness and noted that “simple things such as a cold” lead to hospital admissions. HCPs suggested that children of great medical complexity have survived because of technology and medication advances; however, as a result of their complexity, these children are at very high risk for acquiring illnesses that lead to hospitalization or ED use.

Parents and HCPs perceived that the child's young age contributed to increased risk, citing infants' inability to communicate what was wrong as a barrier to knowing how to respond to the child's illness. In these cases, parents described feeling uncertain about the child's state of wellness or illness and frustration at not being able to concretely identify problems. HCPs observed that infants and young children are easily distressed, often creating barriers to providing treatment efficiently.

Protective Factors—Parents and HCPs discussed very few protective factors related to the individual child. Parents believed that slight changes in the child's physical appearance could indicate a changing condition, triggering a timely response before emergency treatment became necessary. Similarly, parents perceived that children who learned to avoid

factors known to trigger illness such as certain foods, dehydration, and excessive heat or cold were protected against hospital admissions and ED visits.

Parent-Child Relationship

Risk Factors—Parents acknowledged that intense emotions about the child's illness influenced decisions regarding their child's care. Parents described having strong reactions, such as panic, to seeing symptoms of illness in their children that could indicate a serious problem. One mother described her panic when her child becomes ill:

I do freak out when she catch a cold. I do freak out when she start coughing, because that can mean anything. I call the doctor and asks him to set up an appointment and go and get her [the child] checked out, but, yeah, I freak out. I freak out.

Parents described feeling a lack of control, stating that children would catch illnesses and require ED visits or hospital admission regardless of parents' actions to prevent this occurrence. Further, when children did become sick, parents reported feeling limited control over the child's care in the health care setting. One father described his feelings of powerlessness:

The pain and agony of not being able to help her any, just waiting for the doctors to try to help her—that's the most thing that gets to you, it's really up to the doctors to give her the help that she needs. The parent, you can only support her emotionally, you can't really support her medically, so that's the hardest.

Parents perceived that uncertainty placed the child at greater risk, reporting they had great difficulty deciding how quickly to react to a child's illness, and often feeling unsure of their decision as to whether the child should be taken to the ED or the primary care provider (PCP). Parents' feelings of uncertainty also extended to everyday parenting activities, like worrying that washing a child's hair or giving the child a bath might trigger a child's illness, or being certain that the child drank adequate amounts of fluids before going outside to play.

While parents discussed feeling panic and uncertainty, HCPs perceived parents who were overwhelmed and exhausted from caring for the child placed their child at greater risk for hospital admissions or ED visits. HCPs expressed frustration with parents who denied their children had problems and, therefore, did not obtain outpatient and home services for those children. HCPs indicated that parents who knew how to use the system to obtain resources were able to meet their child's needs adequately.

Protective Factors—Parents most commonly discussed the protective nature of their vigilance over their child, and felt a strong desire to protect their children and minimize germ exposure. Parents also attended to precautionary measures, such as ensuring children ate healthy meals and took preventive medications. Parents were constantly watchful of their children and checked on them throughout the night to observe for changes that might indicate a health decline. When the child did appear to have signs of illness, parents believed their swift reaction protected the child from ED visits and hospital admissions.

All parents and HCPs described the protective nature of the parents' knowledge, experience, and education. Parents often described the evolution of this protective factor over time, reporting soon after the child's diagnosis they didn't yet know much about the condition. Parents addressed their lack of expertise by seeking knowledge about the child's condition. One mother described her experiences when her son was newly diagnosed:

It was very educational but it was also hard, and sad, and sometimes depressing
[...] I don't know everything about seizures. But at the same time I'm taking it as an
educational level so I can learn what I need to know for my child.

HCPs believed that parents who had greater understanding of the child's condition promoted better outcomes. Knowledgeable parents were able to react quickly and provide the child with more preventive treatments and therapies at home, minimizing the risk of an ED visit or hospitalization.

Family Structure and Resources

Risk Factors—Family structure often contributed to risk. Parents perceived additional risk from the presence of siblings in the house who increased the potential for exposure to contagious illness. Parents described efforts to keep sick children away from children with CCC, who often required hospitalization for illnesses that would not affect other children so severely. HCPs discussed the effect of split households and households with a single working parent. Children living in these settings were perceived to be at increased risk because a child of a working single mother, for example, might stay with “this grandma today, and this aunt tomorrow,” while a child of divorce might go between parents, increasing complications related to discontinuity of care and miscommunication.

A lack of available resources within families, such as income, telephone access, and transportation, were commonly discussed risk factors. According to HCPs, parents took their child to the ED, where no initial payment was required, rather than the PCP's office where the parents owed money to the PCP. Limited finances also restricted telephone access and affected parents' communication with HCPs. Approximately one-fourth of the parents did not have a home phone, shared a single cell phone, or were limited by number of available cell phone minutes. Some parents also described having a single shared vehicle or a need to rely on other family members for transportation, which affected the parents' decisions regarding where to take their child for care. Therefore, lack of transportation placed children at increased risk as well.

Protective Factors—Parents and HCPs agreed upon the importance of family support in protecting children against hospital admissions and ED visits. HCPs perceived that extended family members who were educated about the child's condition were an essential support to parents and children. Parents often relied on other family members with prior health care knowledge or experience for guidance when making decisions regarding the child's care. HCPs described family members providing respite care so that parents could meet their personal needs for rest and hygiene. Like HCPs, parents emphasized the importance of support from family, but identified additional needs beyond respite care. Parents worried about their other children when one child was in the hospital and relied on family for

childcare. Parents also worried about expenses, and family members often provided financial support. Parents perceived the support received from other family as critical to helping them cope with the child's illness and the associated burdens of care.

Health Care Provider Relationships

Risk Factors—Most parents described multiple communication barriers, ultimately placing the child at risk. Mixed messages from providers, such as varying reports about the child's condition and conflicting information about diagnoses, left parents feeling frustrated and confused. Parents also described receiving conflicting instructions from providers regarding the actions they should take when the child needed health care attention. One parent described receiving contradictory advice:

... she [the specialist] was just telling us when she [the child] does have a fever, take her straight to the emergency room. Now when we get to the emergency room, they tell us it's better to take her to the pediatrician first.

Some parents also felt as though providers told them partial results. A mother and father dyad felt information was withheld from them:

They just tell us what they got to tell us and then they don't say nothin' else. They're secretive about it. [...] Like they [specialists] won't tell us all the results, they'll just tell us part of them and then tell us we got to talk to the family doctor about the rest. But the family doctor don't even tell.

Parents described other communication barriers such as feeling embarrassed to ask questions for fear of sounding “stupid,” particularly early in the relationship with the HCP. One parent described feeling uncomfortable calling the PCP with questions because of the PCP's intimidating demeanor and unfriendly responses to her questions. Parents also described sensing that HCPs did not listen to them or respect their knowledge about the child's condition.

HCPs also described communication barriers. Acute care, primary care, and ED providers believed parents disregarded providers' advice regarding when to take the child to the office versus the ED. This lack of influence over parents frustrated HCPs and was magnified with parents of children who were frequently admitted. HCPs felt this disregard resulted, in part, from parents' mistrust of providers. One HCP described the feelings of helplessness she experienced from repeated encounters some children with CCC had with the health care system:

This is going to be a lifelong thing for them as opposed to a trauma that comes in where you're like, “The kid's going to have to go to surgery and then will be better at some point.” And so that's kind of excruciating I think for us, especially the ones that are in the ER several times a month and just can't seem to get better.

Protective Factors—Both parents and HCPs valued open communication and a strong, positive relationship between parents and HCPs. Parents believed effective, open communication included clear explanations about their child's diagnosis and treatment, having HCPs who listened to them, and feeling comfortable asking questions or calling the

PCP to discuss treatment decisions, such as whether or not to take the child to the ED. Parents described conducting careful searches to find a PCP whom they believed listened to and valued their perspectives as a parent. When good relationships were established, parents not only called the PCP for advice on treatment decisions, but also to discuss the child's condition and ask questions proactively.

HCPs similarly emphasized the importance of communication in building rapport and establishing a strong parent-provider relationship. HCPs perceived that to form a good relationship with parents, providers should be easily contactable, good listeners, and familiar with the child. Essential relationship-building actions included encouraging and promoting parents' sense of confidence in their ability to care for their child.

Health Care System Environment

Risk Factors—HCPs identified risk factors at the health care system-level, such as decreased funding limiting resources available to families. HCPs perceived children with certain types of insurance to be at greater risk because of insurance limitations among providers and coverage restrictions for prescription medications. Further, some children were under-insured because the parents held a minimum-wage job that offered benefits, which made them ineligible for indigent programs. Other system-wide risk factors included a shortage of available, qualified therapists and time constraints in the primary care office, hospital, and ED, inhibiting HCPs' ability to deliver the necessary in-depth education and support.

Protective Factors—Parents primarily perceived health care treatments such as preventive medications and therapy to be protective against hospital admissions and ED visits. HCPs frequently discussed the protective nature of care coordination, case management, and promoting continuity of care. According to HCPs, children with greater medical complexity often have a caseworker who helps the family with decisions pertaining to resource utilization. HCPs identified the benefit of having a case manager/care coordinator who is intensely familiar with the individual child to facilitate communication with specialists, PCPs, school nurses, and others members of the child's care team. One HCP described her thoughts on establishing continuity of care:

If we're able to identify these pediatricians or family care doctors that would be comfortable to take care of these kids, then it's easy, you know? It means that you cannot go to your regular doctor because they're not comfortable, but we found somebody else for you. This is where you'll go. They know what's going on, we forwarded your discharge summary. Then there's some kind of continuity of care.

Community Environment

Risk Factors—Parents and HCPs perceived the lack of community resources to be a primary risk factor. Parents struggled to attend out-of-town appointments due to conflicting obligations such as work. Driving an hour or more to distant urban centers to see a needed specialist was burdensome to parents, and a lack of affordable, reliable public transportation led to missed appointments. Parents sometimes took children to the ED within walking distance rather than going to the PCP's office across town. HCPs confirmed lack of

transportation as a risk factor, since some children missed office visits because the parents lacked transportation or money for fuel.

Parents also frequently discussed the role of exposure to community-acquired illness as a risk factor. Parents were reluctant to take their children to public locations, including daycare, because they feared exposure to contagious illness. Parents believed their children with CCC were more susceptible to catching illness and had more severe outcomes than other children.

Protective Factors—Parents believed support groups to be protective against admissions and ED visits; however, parents also described a frustrating lack of local support groups, websites, and hotlines. Parents said that increased availability of support groups would allow them to exchange knowledge with other parents, learn from each other's experiences, and receive much needed emotional support. HCPs also perceived supportive communities and families to be protective against hospital admissions and ED visits. Yet, in spite of the perceived benefit of support groups, providers believed these groups were difficult to maintain in the community because of a lack of financial support and difficulties with organizing groups.

Discussion

Parents and HCPs often agreed on key risk and protective factors for hospital admissions and ED visits among children with CCC. A model of risk and protective factors as perceived by parents and HCPs is presented in Figure 1.

According to Hawkins et al. (1992), risk factors are associated with poorer outcomes and have varying degrees of modifiability. Protective factors buffer the effect of risk factors on outcomes. Parents and HCPs in this study described risk factors of varying degrees of modifiability. Child's age and the severity of the child's condition, for example, are factors with limited modifiability; parents' emotions and feelings of uncertainty and delivery of mixed messages from HCPs are modifiable. Many of the protective factors described by parents and HCPs could buffer the effect of risk factors on hospital admissions and ED visits in this population of children. For example, among parents of children with similarly severe conditions, those children whose parents have more experience and knowledge may have fewer hospital admissions and ED visits than other parents. Open communication and a strong relationship between parents and HCPs may also buffer the effect of risk factors. Nurses are central members of the health care team, and developing or refining nursing interventions to strengthen these protective factors is imperative.

Parents in this study frequently cited exposure to contagious illness from siblings and from public settings as a risk factor for hospital admissions and ED visits. Nurses can reduce this risk by increasing parents' knowledge of infection control techniques and resources. Organizations such as the Centers for Disease Control (CDC) and the American Association of Pediatrics (AAP) offer guidelines on preventing communicable disease transmission for parents, day care workers, and school employees (American Academy of Pediatrics, 2013; Centers for Disease Control and Prevention, 2011). Nurses may help parents identify

reliable web sites that parents can access repeatedly. Alternately, nurses can print and distribute flyers to parents of children with CCC. Flyers available via the CDC clearly illustrate infectious disease control practices, which may expand adoption of these practices among parents with limited literacy.

Parents' heightened emotions, feelings of uncertainty, and perceived lack of control were also frequently mentioned risk factors that affected parents' decision-making processes and led to increased utilization. Nurses can empower parents and reduce negative emotions by supporting parents' desire for enhanced knowledge and education pertaining to the child's complex chronic condition(s). Knowledge and education may protect children with CCC from hospital admissions and ED visits, but parents often believe they do not receive adequate education from providers (Fredrickson et al., 2004). Furthermore, Burke et al. (1991) found that parents of children with CCC who felt they were lacking adequate information from providers experienced greater stress and sought information to relieve this stress. Clinical and community nurses can combat these negative emotions and potentially reduce avoidable hospital admissions and ED visits by linking parents with valid and reliable educational resources they can access in the health care setting and at home. Resources exist in multiple media and may be chosen to accommodate the parent's preferred learning style. Nurses should consider including other family members besides parents in educational opportunities. Parents who participated in this study cited the protective nature of supportive, knowledgeable family; by including family members in educational sessions, nurses may be able to enhance the availability of this additional support to parents at home.

The lack of education parents felt they received from providers was a compelling finding of this study since patient and family education is a key component of the nursing role. Time constraints may be a formidable barrier to providing in-depth education to parents of children with CCC. Nurses in this study and previous studies cited a lack of time for communicating with patients and parents (Hemsley et al., 2012). This barrier must be addressed since parent and HCP participants in this study frequently reported the perceived protective influence of possessing refined skills for accessing resources and a heightened knowledge of the child's illness. Many possible solutions to this dilemma exist and should be further investigated. One solution may be to employ patient educators in acute and primary care settings who are responsible for enhancing parents' access to educational resources. Another solution may be to assign patients a care coordinator with whom the patient/parent may form a trusting relationship and feels comfortable calling with questions or problems.

Lack of resources was another risk factor frequently reported by HCPs and parents. Children with CCC living in resource-poor neighborhoods with the lowest socioeconomic status are at greater risk for rehospitalization (Wang et al., 2009). Findings from this study suggest the availability of resources affects parents' decision-making regarding accessing health care. Interventions and programs developed in conjunction with parents to improve access to resources and to minimize barriers are needed. In some cases, interventions that increase parents' awareness of available resources should be chosen.

Issues pertaining to ineffective communication were frequently reported modifiable risk factors. In particular, many parents described receiving conflicting messages and instructions from HCPs. This risk factor may be modified through strategies designed to improve collaboration and access to care coordination. One such strategy is the medical/health care home model. The Ad Hoc Task Force on Definition of the Medical Home (1992) and the National Association of Pediatric Nurse Practitioners (2009) released position statements in support of the medical/health care home for children with CCC. The medical/health care home model asserts that children should receive coordinated care based on a strong, trusting parent-child-provider relationship. Parents and HCPs who participated in this study discussed the protective nature of parent-provider rapport and strong parent-provider relationships. Discussions of communication often were accompanied by those of parent-provider relationships and rapport, suggesting communication is an integral part of relationship development among this population. Therefore, actions designed to minimize ineffective communication may have the added effect of strengthening parent-provider relationships, which could further protect children with CCC against hospital admissions and ED visits.

Limitations

Parent participants were recruited from one hospital, and the characteristics and perceptions of parents of children hospitalized at one facility may not reflect those of parents at other facilities. In addition, possible limitations of directed content analysis were as follows: the use of theory may have introduced bias during data interpretation and analysis, participants may have perceived interviewer's cues in a particular way, and some facets of the phenomenon being examined may have been obscured (Hsieh & Shannon, 2005).

Conclusion

Parents and HCPs described risk and protective factors associated with hospital admissions and ED visits spanning multiple levels of influence. These findings may inform future research to test the effect of the risk factors on hospital admissions and ED visits and may also inform research that explores the mediating or moderating effects of protective factors on the relationship between risk factors and outcomes. The results of this study expand current knowledge by contributing parents' perceptions of risk and protective factors that can lead to the development or refinement of interventions tailored to strengthen protective factors and minimize the impact of risk factors on hospital admissions and ED visits. HCPs' perceptions contribute to a greater understanding of the intersection between the health care system and parents' perceived needs. A better understanding of parents' and HCPs' perceptions increases the likelihood that interventions will be successfully adopted and implemented.

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Figure 1.
Ecological model of perceived risk and protective factors for hospital admissions and ED visits among children with CCC.

Table 1
Parent/caregiver demographic data (*n* = 13)

Variable	Percent (<i>n</i>) or Mean $\pm$ SD (Range)
Parent/caregiver Gender	
Male	30.8 (4)
Female	69.2 (9)
Parent/caregiver Race	
White	38.5 (5)
Black	61.5 (8)
Parent/caregiver Ethnicity	
Hispanic or Spanish Origin	7.7 (1)
Parent/caregiver Age in Years	27.1 $\pm$ 7.6 (21–49)
Parent/caregiver Relationship to Child	
Mother	61.5 (8)
Father	30.8 (4)
Grandparent	7.7 (1)
Child Gender	
Male	50 (4)
Female	50 (4)
Child race	
White	37.5 (3)
Black	62.5 (5)
Child Ethnicity	
Hispanic or Spanish Origin	12.5 (1)
Child age in years	1.3 $\pm$ 1.2 (0–3)
Number of Children with More Than one Systems Affected	25 (2)
Child System affected	
Neuromuscular	50 (4)
Respiratory	12.5 (1)
Gastrointestinal	25 (2)
Hematologic or Immunologic	50 (4)
Child use of Device	
No	100 (8)

Table 2
Health care provider demographic data (*n* = 24)

Variable	Percent (n) or Mean $\pm$ SD (Range)
Gender	
Male	8.3 (2)
Female	91.7 (22)
Race	
White	83.3 (20)
Black	12.5 (3)
Asian/Pacific Islander	4.2 (1)
Ethnicity	
Hispanic or Spanish origin	0
Profession	
Physician	8.3 (2)
Registered Nurse	70.8 (17)
Licensed Practical Nurse	4.2 (1)
Ancillary Care Provider	4.2 (1)
Other	12.5 (3)
Specialty/Practice Setting	
Pediatric Primary Care	37.5 (9)
Pediatric Acute Care	37.5 (9)
Emergency Care	20.8 (5)
Other	4.2 (1)
Years Practicing as a Health Care Provider	17.5 $\pm$ 11.1 (4–39)
Years' Experience Caring for Children with Complex Chronic Conditions	15.0 $\pm$ 10.4 (4–38)