Realities of Children with Special Health Care Needs and Disabilities

Cara Sisk and Martha Howard

Sisk, C., & Howard, M. (2024). Realities of children with special health care needs and disabilities. *Pediatric Nursing, 50*(4), 174-184. https://doi.org/10.62116/PNJ.2024.50.4.174

Health care encounters are stress-inducing events across the lifespan. Research highlights the impact of hospitalization on children and suggests methods to facilitate their communication of these experiences to guide health care professionals. Children with special health care needs and disabilities are an overlooked population whose experiences of health care are often unheard of due to idiosyncrasies and exceptionalities. This qualitative study used medical play, body mapping, and interviews with five school-age children who have both special health care needs and disabilities to seek their perceptions of their health care experiences and how these experiences impact them. Inductive and visual analyses yielded three themes pertaining to perceptions of their health care experiences: 1) This is my body, 2) I know the health care environment, and 3) I understand medical treatment. Three themes emerged regarding the impact of these experiences: 1) My diagnosis affects me, 2) I take the good and the bad, and 3) I hurt, and I cry. Findings indicated participants' health care perceptions and impacts were enhanced by combining child-centered data collection methods. Health care professionals may adopt the shared modes to better understand unique realities/perspectives of children's health care experiences to enhance the quality of care provided to all children.

Keywords: Children, special health care needs, disabilities, child life.

Children have received health care in hospitals since the days of the American Industrial Revolution. The pediatric health care system has moved from multiple patient-bed units without parental presence to limited parental visitation to modern-day single-patient rooms and family-centered care where parents are included in medical decision-making (Thompson, 2009).

Winzer (1993) provided insight into the care of children with disabilities during the early days of health care provision in hospitals. The prevalent medical model deemed the child's disability a deficit that required special education interventions provided in separate settings by specialists (Gelzheiser, 1987). Despite emerging medical diagnoses, medical and educational personnel were susceptible to prevailing social and religious judgments regarding individuals with disabilities, which included various superstitions and myths. These factors shaped the development of the institutional complex that emerged, dictating who was institutionalized, where, for how long, and what life in the institution was like. In 1975, children with disabilities, formerly institutionalized for care, were emancipated to live at home with their families, became members of society, and attended school thanks to Public Law 94-142 (Office of Special Education and Rehabilitation Services, 2007).

Children with special health care needs (CSHCN) is a classification in American health and human services (McPherson et al., 1998). The Maternal and Child Health Bureau defined CSHCN as "those who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition 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). The World Health Organization (1993) defined disability as follows: "In the context of health experience, a disability is a restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (p. 143). CSHCN and accompanying disabilities are a vulnerable population (Eddy & Engel, 2008) who require many health care services, such as hospitalization for complex medical needs, and present more psychosocial issues than CSHCN without disabilities (Houtrow et al., 2011).

Capurso and colleagues (2021) presented narratives from children with medical conditions requiring hospitalization. The narratives, analyzed using interpretative phenomenological analysis (IPA), illuminated the necessity of listening to their illness-related experiences that may be shared through various modes. They described a worthwhile means of gaining pediatric health care perspectives.

Additional methods are needed to gain valuable perspectives about

Cara Sisk, PhD, CCLS, *is an Associate Professor, School of Human Ecology, Tennessee Technological University, Cookeville, TN.*

Martha Howard, PhD, IECMH-E®, *is a Professor, Curriculum and Instruction, Tennessee Technological University, Cookeville, TN.*

Acknowledgments: *The authors would like to thank the children who co-constructed this research by sharing their unique realities of pediatric health care experiences.*

Table 1.
Participant Demographic Information

Pseudonym	Age (Years)	Sex	Medical Diagnosis and Disability	Age at Onset	CSHCN-S Category Qualifier
Alex	7	Male	Kidney disease	Birth	Medication dependency, service use, functional limitations
Ben	7	Male	Rare brain stem disorder	Birth	Medication dependency, service use, functional limitations
Dena	6	Female	Ventricular septal defect, atrial septal defect, chromosome deficiency, intellectual disability	Birth	Medication dependency, service use, functional limitations
Emily	12	Female	Juvenile idiopathic arthritis	9 years	Medication dependency, service use, functional limitations
Fergie	9	Female	Unspecified genetic syndrome, developmental delay	Birth	Service use, functional limitations

Note: All participant names have been changed to pseudonyms. CSHCN-S = Children with Special Health Care Needs-Screener.

the health care needs of CSHCN and accompanying disabilities in order to modify and improve practice and quality of care. The purpose of this study was to explore health care perceptions of school-age CSHCN and disabilities using such methods. The goal was to better understand the perceptions and impact of children's health care experiences when they have both a special health care need and a disability diagnosis. Research questions addressed were 1) What are children's perceptions of their health care experiences when they have both special health care needs and disabilities? and 2) How do personal health care experiences impact children with both special health care needs and disabilities?

Materials and Methods

The researcher was guided by a constructionist epistemology from an interpretivist theoretical framework using qualitative methodology. Institutional Review Board approval was granted by the authors' university.

Participant Recruitment and Screening

Using the purposeful sampling approach of snowballing, the researcher identified potential participants. The Children with Special Healthcare Needs Screener (CSHCN-S) (Bethell et al., 2002) was implemented with the primary health care parent (all mothers in this research) to identify five qualifying school-age participants. The CSHCN-S is a criterion-based measure that requires children to meet all three components of a question to screen as having a special health care need: 1) dependency on prescription medicines, 2) use of services about what is typical for most children, and 3) functional limitations. Four of the five participants qualified in all three categories, while one participant qualified in only two categories: service use and functional limitations (see Table 1). The more categories in which a child qualifies, the higher the acuity of needs they present (Bramlett et al., 2009).

After verification of participants' special health care needs from the CSHCN-S and the primary health care parent's confirmation of disability diagnosis, parental consent and child assent were obtained. Each participant's mother was interviewed to provide context regarding their child's health care history and experiences. Participants were five children aged 6 to 12 years, two boys and three girls, who had at least one inpatient admission or equivalent high acuity health care intervention as an outpatient (see Table 1).

Data Collection

This qualitative research used distinct yet varied modalities of data collection specifically incorporated to gather information regarding the children's health care experiences and their impacts. Table 2 outlines the data collection steps.

Semi-structured interviews (see Table 3) relied on verbal communication and expression, allowing the researcher to hear about each child's health care experiences in their own words, giving them a voice to share their stories. Children were asked about a time they went to the doctor or hospital. They were then provided with blank paper and markers to draw these experiences as questions were presented to assist in their information sharing. Children also participated in body mapping, a term coined by MacCormack and Draper (1987). Davy and colleagues (2014) described it as a "life-size representation of self" (p. 232) that uses art-based techniques for sharing personal narratives. Cornwall (1992) identified body mapping as a research method and deemed it useful for understanding individuals' perspectives regarding their bodies. Cornwall (1992) contended that the visual representation allowed for more in-depth interviewing by encouraging participant reflection and articulation.

Table 2.
Data Collection Steps

1. The researcher met with mothers individually to obtain consent and conduct interviews for historical and contextual information.
2. Research session one with each child while the mother was present was designed to establish a relationship and build trust because the researcher and child had never met before. The child's assent was also gained during this first meeting.
3. Research session two with each child individually involved interviewing them and engage them in drawing pictures of their health care experiences and body mapping how they saw themselves.
4. Research session three focused on an individual videotaped medical play session with each child, which included some spontaneous questions from the researcher regarding their play.

Table 3.
Semi-Structured Interview Guide

1. Tell me about a time when you were in the hospital (at the doctor's office).
2. What do you remember about being at the hospital?
3. What did you think about that experience?
4. How did that experience make you feel?
5. Why did you go there?
6. What did you do there?
7. Who did you meet there?
8. Tell me about the doctors and nurses you met.
9. What did it feel like to be there?
10. Was anything easy to do when you were there?
11. Why was it easy?
12. Was anything hard to do when you were there?
13. Why was it hard?
14. Did you or someone else do something to make the hard part easier?
15. What could the doctors and nurses have done to make your time there better?
16. What would you tell other children about going to the hospital or doctor?

Drawings of health care experiences and body mapping provided kinesthetic expression and the creation of visually descriptive representations. Drawings provided information relevant to their health care experiences, and body mapping revealed how each child saw themselves.

Non-directive medical play (Bolig, 1990) and role rehearsal/role reversal play with health care materials and themes (McCue, 1998) provided the children with control over their expression and revealed non-verbal insights into their perceptions of health care experiences. Medical supplies chosen were common items children often see during well-child and sick-child health care visits. Blank cloth body-outline dolls (Gaynard et al., 1991) were used in medical play to represent the children's patients needing health care. Participants were given markers and a blank cloth body-outline doll, told that this was their patient, and asked to draw their patient's face and anything else they desired. They were then introduced to the medical supplies and prompted to do what their patient needed.

Data Analysis

Data analysis included interpretive description, an inductive approach, and visual analysis of the children's interviews, drawings, and medical play. Although mothers' data were not analyzed, selective coding was used to inform pertinent health care histories and provide context for each participant.

Like Capurso and colleagues (2021), this research relied on Piaget's Cognitive Developmental Theory framework to interpret the school-age participant data. The Concrete Operational cognitive level was chosen because participants aged 6 to 12 would engage in medical play while also exhibiting necessary cognitive and verbal communication skills to relay their health care experiences (Piaget, 1967). Rose's (2012) critical visual methodology informed the visual data analysis to consider production, image, and audience. Visual analysis of participants' drawings included consideration of content, color, spatial organization, image size, and orientation to other images (Guillemin, 2004). A developmental approach to children's art provided further insight into the visual analysis of participants' drawings (Kellogg, 1970; Lowenfeld & Brittain, 1987). Visual analysis through the lens of a Certified Child Life Specialist (CCLS) was used during medical play sessions and while reviewing videos of each session to observe children's perceptions and impacts of health care experiences.

Results

The analyzed children's data resulted in six final themes directly related to the research questions. Findings, interpretive themes, and subthemes are organized by the research questions. Participants' pictures, body maps, and medical play descriptions are provided to highlight children's experiences and perceptions within each theme.

Children's Perceptions of Health Care Experiences

Three themes were connected to participants' perceptions of their health care experiences: 1) This is my body, 2) I know the health care environment, and 3) I understand medical treatment (see Table 4).

This is My Body

The "This is My Body" theme allowed the children to construct a tangible, visual representation of themselves. This theme included

Table 4.
Interpretive Themes, Subthemes, and Definitions for Perceptions of Health Care Experiences

Themes and Subthemes	Definitions
1. This is my body. • I can tell you what I know. • Let me show you what I see.	Related to participants' physical bodies.
2. I know the health care environment. • I can describe and explain it to you. • The people I meet.	Health care locations, time, and people working in these environments.
3. I understand medical treatment. • The things done to me. • The things I must do.	Vast array of treatments, procedures, and equipment involved in the participants' care.

two subthemes: "I Can Tell You What I Know," and "Let Me Show You What I See." Participants were afforded opportunities to share about their bodies using various expressive modalities. Medical play often facilitates the child's projection of themselves and their own medical experiences onto a blank-cloth body outline doll. Verbal explanations often accompanied the school-age children's medical play session as they discussed what their doll patient was experiencing. An array of information was shared including eye color, freckles, smiling, or braided hair; sharing these concrete physical characteristics aligned with their current concrete thinking.

I Can Tell You What I Know. Participants provided concrete explanations of health care experiences, including concrete bodily functions. When asked about a time he was at the hospital or a doctor's appointment, Alex, a 7-year-old boy, pointed to the location of his kidney on his body and drew a simple small red (his favorite color) swirl to represent his kidney. He explained, "It gets all the bad stuff, and then you pee it out." He further elaborated, saying, "One time my kidney tried to die," and "another sad thing, I had to get my old, another one. It's my mommy's." Alex's sharing of information about his health care experiences was a strong indication that he had specific knowledge about his body and the medical situations he endured.

Participants recognized medical items during medical play as items they had encountered during health care experiences. They were comfortable with the medical items, likely due to their being in control of these items. Medical play provided a visually and verbally expressive modality for this subtheme, illuminating cognitive developmental differences among participants. Dena, a 6-year-old girl with an intellectual disability, drew on her doll patient but did not verbally identify these markings as related to her health care experiences. She directly demonstrated use of medical items on her physical body, indicating her preoperational thinking. Fergie, a 9-year-old girl with concrete thinking, discussed her medical experiences as she applied markings and bandages to her doll patient. Emily, a 12-year-old girl, displayed formal operational thinking during medical play, drawing on the body-outline doll while verbally sharing her medical experiences related to blood draws and MRIs. See Figure 1 (Sisk & Baker, 2019) for the developmental progression within these three participants' medical play dolls.

Let Me Show You What I See. This subtheme was predominantly revealed through the participants' body mapping activity. Ben, a 7-year-old boy, drew a very concretely identifiable image of himself wearing a green shirt, blue pants, and brown shoes. He included hair, eyes, and a mouth. He then looked at his drawing and said, "Oops. OK. Wait. There," and drew his tracheostomy tube, which seemed to be something he forgot about being part of his physical appearance. This indicated the tracheostomy tube was equivalent to other common body items he drew, which is expected because he had the trach since infancy.

Fergie drew specific items on her body map versus drawing clothing as Ben did, reflecting her further development of concrete operational thinking. She drew braided hair, her glasses, eyes, nose, mouth, and heart; colored in her hands and feet; and drew two red lines pointing to each arm that represented intravenous tubes (IVs). She wrote the word 'happy' next to her smiling face. She drew her heart, saying, "They check my heart," revealing her connection of this internal body part to health care encounters. Fergie held a distinct vision of herself and connected it to her health care experiences.

Emily drew a more graphic representation of herself by writing words, including abstract concepts of love, pain, and hope, instead of drawing physical characteristics, indicating her formal operational thinking. See Figure 2 for the developmental progression within these three participants' body maps.

I Know the Health Care Environment

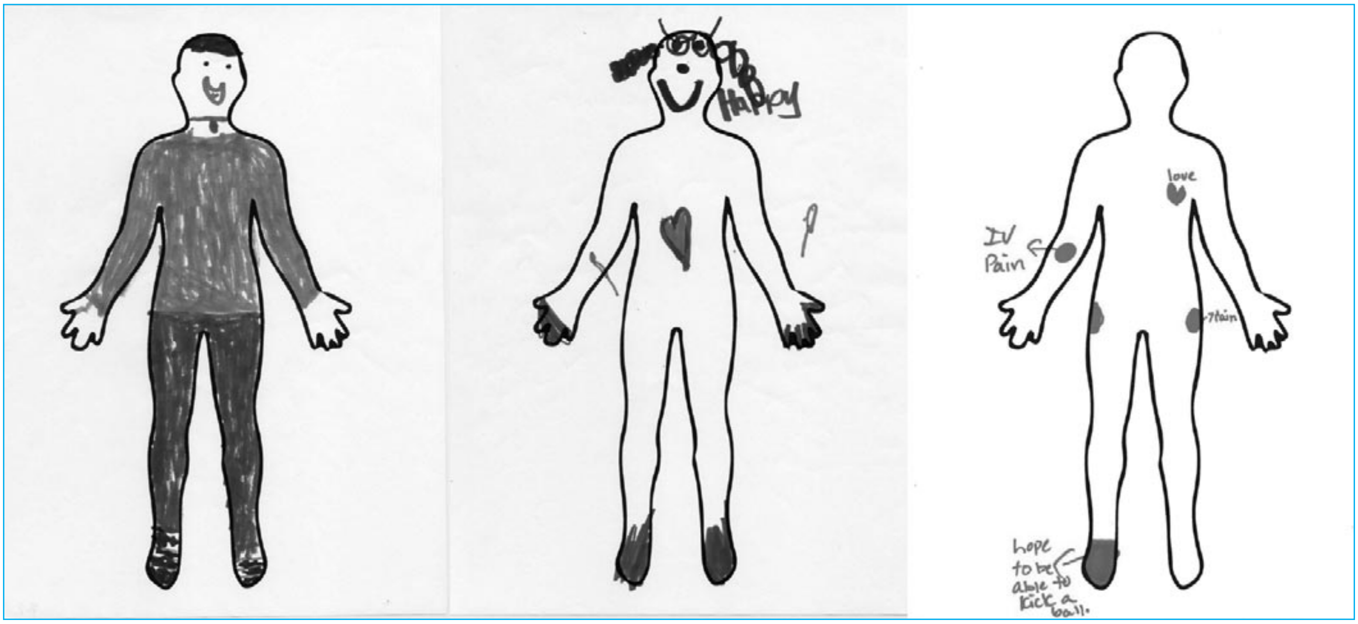
This theme gave participants time to share their perceptions of health care environments, including comments regarding nurses, doctors, locations, communication, time, and frequency. Participants used drawing and medical play to detail their knowledge of the "ins and outs" of the health care and hospital environments.

I Can Describe It and Explain It to You. Participants described health care environments, often unfamiliar, as they explained reasons for being admitted. Alex described it as, "That's where my kidney tried to die," and created a drawing of the hospital with a helicopter on top (see Figure 3) because he had flown to the pediatric hospital "just once." Fergie drew a picture of her hospital room, including herself, her doctor, the door, windows, and the bathroom (see Figure 4). She reported, "I went to the hospital

Figure 1.
Developmental Progress of Dena's, Fergie's, and Emily's Medical Play Dolls

Source: Sisk & Baker, 2019. Reprinted with permission from Information Age Publishing.

Figure 2.
Developmental Progress of Alex's, Fergie's, and Emily's Body Maps



to have my tonsils taken out. We stayed for like one day to sleep over there."

The People I Meet. Participants included medical professionals who interacted with CSHCN and disabilities who impacted the quality of their medical care. Dena, despite her intellectual disability, discussed both a nurse and identified another medical professional, saying, "And she was my doctor." Fergie stated, "I knew my nurses" and called her pediatrician "really nice" while sharing her doctor's role, "She listens to my heartbeat, get a checkup, when I'm sick, I go there." Participants shared further identification of health care staff in medical play, identifying with roles of doctors and nurses during play.

I Understand Medical Treatment

This theme, which has two subthemes of "Things Done to Me" and "The Things I Must Do," shares a well-developed understanding of childhood illness and the role of medical professionals in their day-to-day well-being. Medical play, a key expressive modality for this theme, provided an outlet for all participants to engage with the

Figure 3.
Alex's Drawing of the Emergency Transport Helicopter Landing on the Hospital

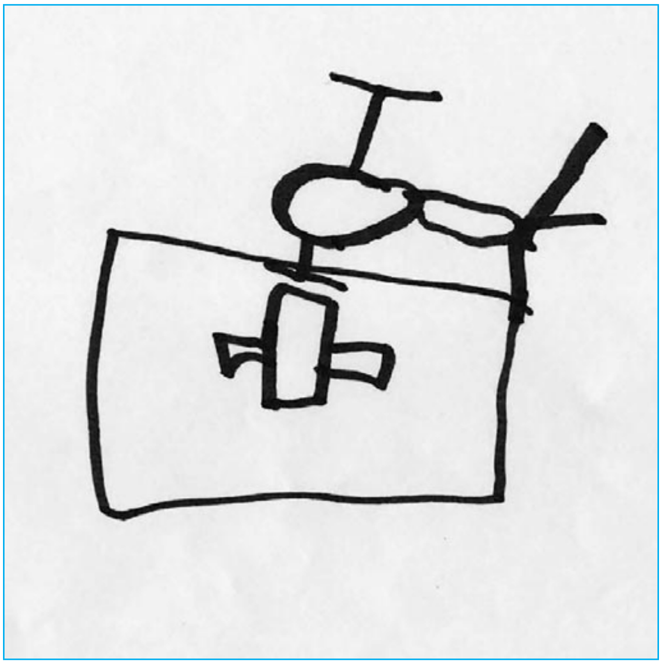


Figure 4.
Fergie's Drawing of Herself and Her Doctor in the Inpatient Hospital Room

medical equipment. Each participant explored the medical items through play, demonstrating their understanding of the equipment. The use of medical play, specifically role reversal/role rehearsal, allowed participants to take on the role of a medical professional, including their power and control.

The Things Done to Me. Within this subtheme, concepts of having medical staff provide medical interventions were predominant. Alex stated, "Oh, well, they did chemo on me," and Ben shared, "I was talking about the thing that they stick something in your arm and like take blood out." Dena recalled, "She gave me the medicine" when talking about the nurse, and Fergie provided several statements, including "They did my shot on here. They checked my blood sugar. They did the shot again, and she gave me medicine." These statements from school-age participants concretely conveyed that health care professionals had provided direct medical care to them.

The Things I Must Do. This subtheme highlighted areas of care they were responsible for or accomplished with family support. Alex showed medications he took daily, saying, "Usually, all the time, I take these medicines. But sometimes, I take Benadryl, and those are right here. These are the kinds every morning. Every day, I have to do all this." Even at 7 years old, he was very well-informed regarding his medications and the responsibility he bears to take them consistently. Emily was cognizant of things she must do for herself, primarily managing her arthritis and pain prevention. She said, "You have to stretch and take medicine. Those are two things that I do. I take medicine every Saturday morning. And the stretch I try to do every day, but sometimes I just forget." Both participants held intrinsic motivations regarding their health care routines.

Impacts of Their Health Care Experiences

Three themes focused on impacts of their health care experiences: 1) My diagnosis impacts me; 2) I take the good and the bad; and 3) I hurt, and I cry (see Table 5).

My Diagnosis Affects Me

This theme included various aspects related to participants' experiences with their diagnoses. Children's explanations ranged from descriptions of minor physical symptoms to more in-depth cognitive and psychosocial processing of diagnosis uncertainties.

It Is Part of My Life. Impacts of the children's health care experiences on their lives were evident among participants. Alex mentioned getting dizzy, a minor symptom. Yet he also dealt with the significant question of "What if they say it's going to be OK, but it's not? Well, when they say it's not going to be all better." Although a concrete thinker, he was processing quite an abstract concept, the impacts of his health care realities.

Emily, with logical reasoning skills, discussed her suspected diagnoses, the process for ruling out diagnoses, and her ultimate diagnosis of juvenile idiopathic arthritis, along with possible future impacts of the diagnosis on her life, including her eyesight, pain, medicines, and possible remission. These impacted her life by interfering with her ability to play sports because sometimes even walking was painful.

Table 5.
Interpretive Themes, Subthemes, and Definitions for Impacts of Health Care Experiences

Themes and Subthemes	Definitions
1. My diagnosis affects me. • It is part of my life. • I tell people my story. • My hopes and wishes.	Aspects related to the participants' experiences with their diagnoses.
2. I take the good and the bad. • Things I find good or easy. • Things I find bad or not easy.	Things participants defined as positive or negative.
3. I hurt, and I cry. • I find ways to cope. • If I could make things better.	Participants' physical pain and crying (an expression of physical or emotional pain) and the various things, including advice, that helped them cope.

Figure 5.
Emily's Drawing of Her Hopes and Wishes

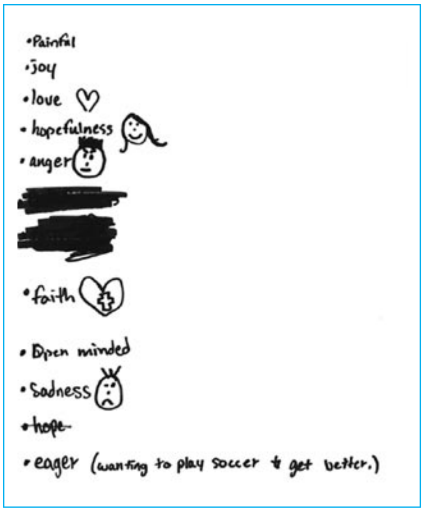


Figure 6.
Alex's Drawing of a Bad Day at the Hospital

I Tell People My Story. All of the children shared their health care experiences, regardless of age or cognitive stage. Dena, who has an intellectual disability, said, "It was burn," referring to the pain of a recent urinary tract infection that required a late-night emergency department visit. Alex concretely shared impacts of his diagnosis and health care experiences by pointing to his body to indicate the locations of his kidneys, port, and G-tube.

Emily discussed that she had to tell her peers and acquaintances about her diagnosis because of the "dramatic limp" and because "I was on crutches for a very long time." Regarding the individuals who know about her diagnosis, she stated, "My closer friends do, but I don't really ever bring it up. If people ask me why I was out of sports for so long, I tell them." As expected for a pre-adolescent, social awareness of differences from peers was a concern; however, with visible signs of the diagnosis, its impact causing her absence from sports participation required Emily to share her health care story.

My Hopes and Wishes. Being the only participant in the Formal Operational Stage of cognitive development, Emily presented a unique perspective, likely because of her ability to think both logically and abstractly. When asked what she would change, she said, "Not having arthritis." Her thoughts about her future were, "I think it's going to get a lot better. It's like starting to calm down now, so in high school, I think it will." When asked to write or draw about her hopes and wishes, she verbalized "to get better" and "hope for getting back to playing soccer" (see Figure 5). This drawing activity revealed that despite the unwanted impacts of Emily's diagnosis, she possessed hopes and wishes for her life.

I Take the Good and the Bad

This theme included the participants defining their health care experiences as good, easy, bad, or not easy, revealing positive and negative impacts.

Things I Find Good or Easy. The blood pressure cuff was identified by Ben as "It's easy," and Alex said, "Ooh, I love these," during medical play. Alex and Fergie both said that taking medication was good or easy.

Ben drew a blue popsicle as something that made him happy at the doctor's office or the hospital. Alex stated that a good day at the hospital is "when I'm just getting a check-up, nothing happening."

Things I Find Bad or Not Easy. Alex "didn't like it," referring to going to the hospital. See Figure 6 for Alex's drawing of a bad day at the hospital. Alex also shared that having a Foley catheter was a bad thing. He then shared a bad interaction with the nurse inserting the catheter: "But one, one nurse was trying to do that. I was screaming; she held me down. She thinks I was a fighter, but I wasn't." He also identified shots as being difficult: "You know the thing that is really hard? Shots. Flu shots. Because I usually get them in my leg, they hurt. Like a bee sting."

Like Alex, Ben also identified the negative impact of needle sticks. In response to being asked to draw something that made him unhappy at the doctor's office or hospital, he drew a detailed syringe with a needle, including lines and numbers for dosing the medication (see Figure 7).

I Hurt, and I Cry

Participants' pain, both physical and emotional, as well as crying as

Figure 7.
Ben's Drawing of Something that Makes Him Not Happy at the Doctor's Office or Hospital

an expression of this pain, along with other ways they coped with health care experiences, were included in this theme.

I Find Ways to Cope. Impacts of the children's health care experience were revealed in this theme. Referring to a time when a nurse held him down, Alex shared, "She thinks I was a fighter, but I wasn't, and then Daddy said, 'Let go.'" This is an example of parental advocacy that supported the child's coping. Alex also shared an example of his mother's support: "Lie, just hold still; it will only hurt for a few minutes or a minute or a second or something like that, so it may feel kind of calming." When asked how he makes things better for himself, Alex said, "Well, not really." Ben also relied on his mother for coping support with painful IV blood draws, saying, "Sometimes I watch, I always watch, but sometimes I hold my mom's hand and stuff." Fergie shared: "Look away because mom always says don't look at it." These examples of coping indicate the significance of parental support for school-age children's coping with health care experiences.

Alex identified crying as something he did when feeling pain. "Well, I cry. Nothing makes me want to cry, but sometimes I cry because it might hurt. So, if it might hurt, but it might not, so I cry just in case it might hurt. Sometimes I fuss because I don't know if it's going to hurt or not." Although he used crying for both physical pain and emotional uncertainty, he was unable to identify crying as his coping mechanism. When told crying is OK, he said, "No, it is not; I don't want to cry." Despite his belief that crying is unacceptable, he ultimately said, "Everything that hurts makes me cry."

If I Could Make Things Better. Realizing the significant impacts their health care experiences were having on the children, it became important to provide them with an opportunity to share their knowledge on how to help other children with similar health care experiences. Thus, during interviews, participants were asked how medical professionals could improve health care experiences for children and what advice they would give to other children going to the doctor or hospital. Children were able to give advice for other children regarding health care experiences, indicating their ability to cope. They were also asked what advice they would give to parents of children in health care situations. To ensure the children's voices were heard without interpretation, verbatim data from the five school-age participants were combined to create a pastiche titled, "If I Could Make Things Better" (see Figure 8). This pastiche reflects their unique realities in their own voices.

Discussion

Results of interviews, body mapping, and medical play revealed the unique realities that exist for CSHCN and an accompanying disability. Sartain and colleagues (2000) identified their child participants as "competent interpreters of their world" (p. 913). The children's perspectives of their health care experiences revolved around their physical bodies, the health care environments visited, and medical treatments experienced. Interviews, body mapping, and medical play allowed for a co-construction of experience.

Children's Understanding of Illness

Capurso and colleagues (2021) used a Piagetian framework to interpret their participants' drawings during the secondary data analysis. They discovered that not all of the children's drawings could be analyzed from a cognitive perspective and recognized that a socio-constructivist model was required to explain some children's illness understandings. Although Piaget's Theory of Cognitive Development was a guiding framework in this research, the constructionist epistemology allowed the participants' meaningful health care realities to develop from their interactions in these experiences. The interpretivist theoretical perspective also included social construction that allowed the children's unique health care realities to emerge, and various expressive modalities of interviews, body mapping, drawings, and medical play revealed their perceptions.

The Importance of Relationships and Coping

Overlap with Capurso and colleagues (2021) includes the presence of a primary caregiver, the chance to establish meaningful relationships, and play. For CSHCN and an accompanying disability, reliance on a primary caregiver for support and building relationships with doctors and nurses were key to achieving greater comfort within the health care environment.

The Power of Play

Play was central to illuminating

Figure 8.
Pastiche of Advice from Participants

If I Could Make Things Better

Pastiche of Advice from Participants

Advice for Medical Staff

Stop doing shots.

Try to make them calm – It [doesn't] work, try something else. Like give them toys that they can borrow, and then they can use them for other kids or they can give them toys that they can keep.

Maybe more things to do (for fun).

Be sure to connect with the kids first, gain the kids' trust.

Talk to them.

Call their names and they can come back.

People have to help you, too.

Advice for Child Patients

It's going to be ok.

Do what your doctors say.

Pray.

Find things you can do.

Get a good couple of books and read a lot and watch a couple of shows.

Talk to parents so you don't just have to sit there.

Hold your mom's hand.

Don't be scared.

Be happy.

Advice for Parents

Leave them *alone* *for a while,*

stay with them, and

talk to them to make sure they are comfortable.

unique realities of participants because medical play was essential in gaining a better understanding of children's health care experiences. Play performs a vital role in the lives of children. Piaget and Inhelder (1969) believed it to be important for children's "affective and intellectual equilibrium" (p. 58). Piaget and Inhelder (1969) argued that play served as a child's break from adapting to life's realities. Imitation in play serves to assimilate reality to self. Piaget explained this concept of "play, which transforms reality by assimilation to the needs of self" (p. 58). Medical play provides a balance between the affective and intellectual domains while also offering children the ability to adapt to their health care reality and assimilate their individual needs.

Implications for Clinical Practice

Children with special health care needs and disabilities possess uniqueness when it comes to their health care experiences that sometimes present as challenges for everyone involved – the child, their family, and health care professionals – because they lack an established relationship. Although parents know their child best, it is valuable to learn the children's direct perspectives of health care experiences to improve the care encounters.

A new theme of advice and coping was specific to the experiences of CSHCN who have an accompanying disability, which differed from Capurso and colleagues (2021). Children were empowered through their unique realities to advise other children regarding their health care experiences, aiding their ability to cope.

Each of the seven participant recommendations specifically applies the Advice for Medical Staff (see Figure 8) to pediatric nurses. First, while "stop doing shots" may seem like an impossibility, knowing that needle interventions are stressful experiences for CSHCN and disabilities, just as they are for most children in health care, provides valuable information. Pediatric nurses tasked with providing needle interventions, which are associated with hurt and pain, should assess every possibility for easing the hurt and pain the children will experience physically and emotionally. For example, are there remedies to numb the area like creams, cold sprays, or the Buzzy device, to reduce pain?

A participant's second recommendation to "try to make them calm" includes a list of ideas to try, including providing toys for comfort. In this statement, the child participant understands that children find toys comforting and correlates this to the ability to help children calm during stressful health care experiences. The "maybe more things to do" item indicates the health care environment is not child-friendly, which can be easily remedied by offering children fun things to do. Although this is often included in the role of CCLSs when present on the health care team, pediatric nurses can incorporate playful interactions into their routine reas of interest, letting them talk about these interests, incorporating play into interactions by singing songs, using impromptu 'I Spy' games for items in the room, or simply placing a toy on the stethoscope for the child to focus on during examinations.

The last four participant recommendations are related: "Be sure to connect with the kids first, gain the kid's trust," "Talk to them," "Call their names and they can come back," and "People have to help you too." Each of these areas inclnships with the children themselves, not only the parent or caregiver who accompanies them. Pediatric nurses are often one of the first health care team members children meet in health care settings; therefore, calling children by their name is the first step in building rapport with the child. Talking to the child specifically provides the opportunity to connect with the child and gain their trust in the intimidating health care environment. This leads to children realizing the nurse is there to help care for them despite the stress the child and family experience. The pastiche in Figure 8 of ways these CSHCN and disabilities participants recommended improving pediatric health care is invaluable for nurses and fellow health care team members.

Participants in this study provided a lens through which to view their health care experiences. Health care professionals, specifically pediatric nurses, are uniquely positioned to enhance positive health care experiences for children by building personal relationships founded in trust when allowing time to talk, learn about the family, and the ever-evolving health care experience for a CSHCN. The nurse may provide explanations and preparation for medical treatment to both children and their parent/primary caregiver. While providing an explanation and preparing for the medical treatment, a pediatric nurse could provide time for a child to engage in health care drawings, body mapping, and discussion of these drawings to become more in touch with their concerns, fears, or preferences. Within the drawing/body mapping context, the child shares their feelings in varied modes of communication and can be heard by the health care professional through a new avenue. Nurses may be able to engage with families in a new and innovative way by providing them with a foundation for a trust-based relationship within which to grow.

Although valuing this approach, the researcher also understands the reality of time constraints that occur within the health care world. While health care drawings and body mapping are useful strategies to learn more about a child's health care experience, it is quite useful to simply engage in a dialogue about past experiences, positive experiences, and areas for growth on the part of the health care team, such as 1) Tell me about your concerns, 2) What would you like to share that might shed light on your needs? 3) What has this experience been like for you in the past? 4) How might we make your experience better than the last? and 5) Is there anything about this that you fear or worry about? In addition, when CCLSs are on the health care team, these psychosocial practitioners are available to provide support for benefit of the team, child, and family.

Children with special health care needs rely on their parent/primary caregiver for support. Each child should have the right to learn about medical interventions on their developmental level within their emotionally secure child-parent dyad. Medical intervention learning cannot take place without the health care professional's willing and open approach to gathering information to further impact practice. The strategies shared here, along with new and innovative strategies, help fine-tune and enhance high-quality health care practices. It is recommended that research continue with CSHCN to continually gain perspective to strengthen pediatric health care practices.

Future Research

Opportunities for future research inquiry related to CSHCN and disabilities still exist. Although not the focus of this research, participants' mothers provided rich data regarding their child's health care experiences. Research focused on the mothers of children in this population is powerful for informing pediatric health care professionals on best practices.

Another area of research sparked from this inquiry is CSHCN and intellectual disabilities. Dena was the only participant with an intellectual disability, which seemed to exacerbate her health care encounters. During one research visit to Dena's home, her father shared how difficult it is to witness health care professionals judge his daughter's behavioral reactions to health care experiences because of her intellectual disability. Specific research on this population would provide valuable insights into health care provision to facilitate coping. Researching perspectives of fathers of CSHCN and disabilities would extend this research.

Limitations

The participant sample was a limitation. Although participants were diversified by diagnosed disabilities, the group was homogeneous because participants were Caucasian, identified as Christian, and lived in the Southeastern United States.

Conclusion

Results of this research add to the rich narratives shared by Capurso and colleagues (2021) and offer additional practice implications for professionals who interact with children during hospitalization by including CSHCN with disabilities as part of the population of care. Results also emphasize the importance of listening to the many voices surrounding CSHCN and disabilities as family advocacy becomes central to high-quality and specialized care.

The significance of this research impacts the work of pediatric nurses, Child Life Specialists, and fellow medical team members. CSHCN and disabilities often have exceptionalities that require individualized patient care. When engaged with respect, flexibility, and a willingness to learn, CSHCN teach health care professionals their unique realities during health care experiences.

References

Bethell, C., Read, D., Stein, R., Blumberg, S., Wells, N., & Newacheck, P. (2002). Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics, 2*(1), 38-48. https://doi.org/10.1367/1539-4409(2002)002%3C0038:icwshc%3E2.0.co;2

Bolig, R. (1990). Play in health care settings: A challenge for the 1990's. *Children's Health Care, 19*(4), 229-233. https://doi.org/10.1207/s15326888chc1904_6

Bramlett, M.D, Read, D., Bethell, C., & Blumberg, S.J. (2009). Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. *Maternal and Child*

Health Journal, 13(2), 151-163. https://doi.org/10.1007/s10995-008-0339-z

Capurso, M., di Castelbianco, F.B., & Di Renzo, M. (2021). "My life in the hospital": Narratives of children with a medical condition. *Continuity in Education, 2*(1), 4-25**.** https://doi.org/10.5334/cie.12

Cornwall, A. (1992). Body mapping in health RRA/PRA. *RRANotes, 16*, 69-76. https://www.iied.org/sites/default/files/pdfs/migrate/G01449.pdf

Davy, C., Magalhaes, L., Mandich, A., & Galheigo, S.M. (2014). Aspects of the resilience and settlement of refugee youth: A narrative study using body maps. *Cadernos de Terapia Ocupacional, 22*(2), 231-241. http://doi.org/10.4322/cto.2014.045

Eddy, L.L., & Engel, J.M. (2008). The impact of child disability type on the family. *Rehabilitation Nursing*, *33*(3), 98-103. https://doi.org/10.1002/j.2048-7940.2008.tb00212.x

Gaynard, L., Goldberger, J., & Laidley, L.N. (1991). The use of stuffed, body-outline dolls with hospitalized children and adolescents. *Children's Health Care, 20*(4), 216-224. https://doi.org/10.1207/s15326888chc2004_4

Gelzheiser, L.M. (1987). Reducing the number of students identified as learning disabled: A question of practice, philosophy, or policy? *Exceptional Children, 54*(2), 145-150. https://doi.org/10.1177/001440298705400207

Guillemin, M. (2004). Understanding illness: Using drawings as a research method. *Qualitative Health Research, 14*(2), 272-289. https://doi.org/10.1177/1049732303260445

Houtrow, A.J., Okumura, M.J., Hilton, J.F., & Rehm, R.S. (2011). Profiling health and health related services for children with special health care needs with and without disabilities. *Academic Pediatrics, 11*(6), 508-516. https://doi.org/10.1016/j.acap.2011.08.004

Kellogg, R. (1970). *Analyzing children's art*. National Press Books.

Lowenfeld, V., & Brittain, W. (1987). *Creative and mental growth* (8th ed.). Macmillian Publishing Co.

MacCormack, C.P., & Draper, A. (1987). Social and cognitive aspects of female sexuality in Jamaica. In P. Caplan (Ed.), *The cultural construction of sexuality* (1st ed., pp. 143-165). Routledge.

McCue, K. (1988). Medical play: An expanded perspective. *Children's Health Care, 16*(3), 157-161. https://doi.org/10.1207/s15326888chc1603_5

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J.M., Shonkoff, J.P., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*(1), 137-140. https://doi.org/10.1542/peds.102.1.137

Office of Special Education and Rehabilitation Services. (2007). *History twenty-five years of progress: In educating children with disabilities through idea*. https://eric.ed.gov/?id=ED556111

Piaget, J. (1967). *Six psychological studies*. Random House.

Piaget, J., & Inhelder, B. (1969). *The psychology of the child*. Basic Books, Inc.

Rose, G. (2012). 'The good eye.' *Visual methodologies* (3rd ed., pp. 51-80). Sage.

Sartain, S.A., Clarke, C.L., & Heyman, R. (2000). Hearing the voices of children with chronic illness. *Journal of Advanced Nursing, 32*(4), 913-921.

Sisk, C., & Baker, J. (2019). Medical play: From intervention to participatory research. In I.R. Berson, & M.J. Berson (Eds.), *Volume 7: Participatory methodologies to elevate children's voice and agency.* Information Age Publishing.

Thompson, R. (2009). *The handbook of child life: A guide for pediatric psychosocial care*. Charles C. Thomas.

Winzer, M.A. (1993). Physicians, pedagogues, and pupils: Defining the institutionalized population. *The history of special education: From isolation to integration* (pp. 145-169). Gallaudet University Press.

World Health Organization. (1993). *International classification of impairments, disabilities, and handicaps: A manual of classification relating to the consequences of disease*. Author.