

HOSPITAL TO SCHOOL TRANSITION: THE EXPERIENCE OF CAREGIVERS OF
CHILDREN WITH DISABILITIES AND SPECIAL HEALTHCARE NEEDS

by

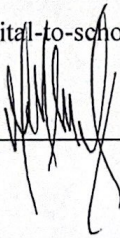
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The transition from hospital to school settings can be a challenging process for individuals involved, particularly for children with disabilities and special healthcare needs and their caregivers. Hospital and school personnel often report feeling unprepared to support the child during this transition, which may increase uncertainty for the child and their families. Research suggests that there is no streamlined process in place for most families, and much of the communication between hospitals and schools falls short if families are unsure how to advocate for these conversations. To better understand the needs of these families, we conducted a survey asking caregivers of children with disabilities and special healthcare needs about their opinions on how school systems address the transitional needs of the family. The results indicated that caregivers feel there is a lack of support and knowledge from school personnel regarding the needs of the child as they transition back to the school setting. Caregivers often feel isolated during the transition, as they are unaware of the resources available to them and feel they must communicate with both the hospital and school settings without support. The study discusses practical implications for caregivers and school personnel and suggests future research directions for the hospital-to-school transition.

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Thesis


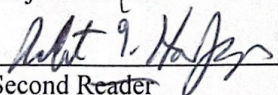
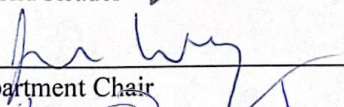
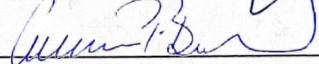
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CHAPTER I

INTRODUCTION

According to the National Survey of Children's Health Data Brief (NSCH, 2022), approximately 14 million students under the age of 18 in the U.S. have special healthcare needs. It has been estimated that one-fifth of households in the United States have one or more children with special healthcare needs (Cohen et al., 2018). Children with special healthcare needs tend to show higher levels of disengagement with the school setting, as they lack motivation and willingness to be active participants in academic success (Barnard-Brak et al., 2017; O'Connor et al., 2014). These children are often at increased risk of chronic, physical, developmental, behavioral, or emotional conditions, and require health and related services in schools (NSCH, 2022; O'Connor et al., 2014).

For some students, this situation is further complicated when they also have a disability (Brown & Kalaitzidis, 2013). While studies examine the large number of children with special healthcare needs, there is a lack of research on those who also have disabilities (Graaf & Gigli, 2022; Morton et al., 2021). Yet, 30-50% of children with intellectual disabilities present comorbidities (Einfeld et al., 2011), which may cause an increase in hospital visits throughout their schooling years (Brown & Kalaitzidis, 2013). Some examples of these comorbidities include epilepsy, anxiety, sleep, vision,

communication, and feeding disorders, as well as increased rates of psychological disorders (Gautam et al., 2014). Furthermore, some children with disabilities, like those with Down syndrome, often present unique characteristics, such as congenital heart disease, vision impairments, hearing loss, hypothyroidism, blood disorders, infections, hypotonia, and sleep disorders (Newton, et al., 2015). These health conditions may increase the length and frequency of hospital visits for these students. To optimize health and wellbeing, medical care for these comorbidities requires ongoing medical surveillance (Reddihough et al., 2021). The increased rate of comorbidities among children with disabilities escalates the risk of unrecognized symptoms, misdiagnoses or delays in diagnoses, communication breakdowns, and poor experiences with healthcare professionals (Ong et al., 2022).

Caregivers of children with disabilities often experience greater levels of physical and mental fatigue, as well as increased financial stress (Kimura & Yamazaki, 2013; Romley et al., 2017). The chronic stress of caregiving for a child with disabilities and medical needs can have serious, lifelong impacts on the health of caregivers (Cohen et al., 2018; Romley et al., 2017). In fact, it has been suggested that caregivers of children with disabilities spend more than 57 hours per week caring for their child (Kuo et al., 2011), and these hours increase with prolonged hospital stays that keep students from being able to attend school (Kuo et al., 2011). The extra stress that is placed on caregivers only heightens when they are tasked with providing much of the medical care for their child as they transition back to school.

Over the years, medical care practices have decreased the length of hospital stays (Shaw & McCabe, 2008; Sturm & Bao, 2000). This in short has transferred

responsibilities of care from hospital to outpatient facilities or schools (Shaw & McCabe, 2008). These practices have created a unique experience for children and their families, during their school-aged years, as the responsibility of transitioning back into the school system often falls solely on the caregivers (McAvoy & Haarbauer-Krupa, 2019). When considering families of children with disabilities and special healthcare needs, the burden added to the caregivers has, consequently, increased the stress on a family (Faw, 2018). While the transition for students with disabilities and special healthcare needs can be quite complex, partnerships are essential to ensure the safety and success of the child in school (McClanahan et al., 2015; Pufpaff et al., 2015).

The current practices of sending children home quicker after a hospital visits, have caused children with healthcare needs to have less access to hospital-school teachers, psychologists, and therapists (Shaw & McCabe, 2008). Only for those students who receive inpatient rehabilitation, will communication between the medical and the school personnel exist (Edelstein et al., 2017; Todis et al., 2018). Unfortunately, compared to their counterparts without disabilities, children with disabilities and special healthcare needs are more likely to experience unmet health supports (Brown & Kalaitzidis, 2013; NSCH, 2022). A reason for this discrepancy may be due to the lack of training for medical professionals (Ong et al., 2022) and the geographical location of children with disabilities and special healthcare needs (Graaf & Gigli, 2022).

Many caregivers feel that they are left accountable for sharing information between the hospital and the school as lines of communication are often muddled (Davies, et al., 2021; Lundine et al., 2020; McAvoy & Haarbauer-Krupa, 2019). Caregivers become frustrated when teachers lack knowledge of health needs as the child

transitions back to school (Lundine et al., 2020; Todis, et al., 2018). Often a similar situation occurs in hospital settings, as hospital staff often fail to accommodate to support a child's disability due to lack of staff training (Ong et al., 2022; Smith et al., 2021). In fact, hospital staff have reported inexperience and low comfort levels when working with children with disabilities (Ong et al., 2022). Blizzard and colleagues (2015) found that, only 39% of the personnel followed up and had any line of communication with the caregivers, and only 10% contacted the school to coordinate the transition process, but this study did not mention the school's role in the transition.

Caregivers' satisfaction with the hospital to school transition process often depends on how responsive they felt medical and school personnel were to their child's needs (Edelstein et al., 2017; Ong et al., 2022). Constructive communication is essential to effectively support these children. Caregivers, health professionals, and the schools should all be communicating, thereby reducing caregiver stress (Andersson et al., 2016; Edelstein et al., 2017). Caregivers stress only increases when they are tasked with being the primary communicator between hospital and school (Todis et al., 2018).

The Transition from the hospital to school can be challenging for the child and family, as the social and emotional needs of the child can be greatly affected. Research has been conducted on these children's experiences in the hospital, but questions remain about what role school personnel can play in the hospital-to-school transition. To identify ways to better support children with disabilities and special healthcare needs and their families, this study explored caregivers' perspectives on the transition. We tried to determine potential gaps in the transition back to school, if supports are needed, and outline potential recommendations for future practices. The questions we provided to

participants included: (a) What do you feel was best addressed by the school during your child's re-entry into the school system post-hospitalization? (b) What do you feel was unaddressed by the school during your child's re-entry into the school system post-hospitalization?

CHAPTER II

METHOD

Participants

The present study recruited caregivers of children and young adults between the ages of two and 22 with disabilities and special healthcare needs from across the United States. Inclusion criteria were set to collect experiences from caregivers with specific characteristics, including being the primary caretaker of an individual with disabilities, which were defined as children who need special education and related services due to a variety of disabilities, including but not limited to intellectual disability, hearing impairment, speech or language impairment, visual impairment, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, specific learning disabilities, and multiple disabilities (IDEA Section. 300.8, 2004). The primary caregiver of an individual with special healthcare needs, which referred to as an individual who has or is at increased risk for chronic physical, developmental, behavioral, or emotional conditions (CDC, 2021) was also included. Primary caregivers were defined as a parent, family member, or legal guardian who oversaw the individual's well-being.

A total of 235 caregivers responded to the survey, of which 74 caregivers responded to the short answer section of the survey. The majority (95.90%) were parents (mothers and fathers), with (4.10%) categorized as legal guardians. Caregivers ranged in

age from 39 to 50+. Approximately, a quarter (24.30%) of the caregivers were 39 or younger, and the majority were in their 40's (44.60%). Most (87.80%) caregivers were White, and the least (1.4%) were American Indian or Alaska Native, Asian, or Black or African American. Approximately 78.40% of caregivers reported being in a relationship, with less than a quarter (21.60%) identifying themselves as single. Less than a quarter (21.60%) of caregiver's household income was \$49,999 or less, and about half (51.40%) had an income of \$100,000 or more. The least number of caregivers (24.30%) reported having three or more children, with the majority having one child (40.50%). Most of the caregivers (78.40%) reported having a part-time or full-time job, and only 21.6% reported not working (i.e., retired, unemployed, raising children full-time).

The children that the participants cared for fell into various disability categories. Most of the caregivers reported having a child with developmental delays (n = 42) and intellectual disabilities (n = 30), and other health impairments (n = 39), with the least number reported having a child with traumatic brain injury (n = 5) or Williams syndrome (n = 1). Other disabilities that caregivers reported included cerebral palsy (n = 14), autism spectrum disorder (n = 29), orthopedic impairments (n = 25), and visual impairments (n = 21). The medical diagnosis of these children fell into multiple categories, but most of the caregivers reported having a child with a chronic illness (n = 32), genetic condition (n = 35), or congenital defect (n = 27). The smallest group of caregivers reported having a child with an acquired illness or injury (n = 8), an acute illness (n = 4), or an acute injury (n = 1). These children ranged in age from two to 22, with the smallest group (9.50%) of kids in early childhood (two to four years), and the largest group (27.00%) in high school (14-18 years). The caregivers' children were placed in a variety of school settings, with a

Table 1*Participant and Child Demographics*

Demographic	<i>N</i>	<i>n</i>	%
Relationship to Child	74		100.0%
Parent		71	95.90%
Other		3	4.10%
Parent Age	74		100.0%
≤39		18	24.30%
40's		33	44.60%
≥50		23	31.10%
Child Age	74		93.30%
not specified ¹		5	6.75%
birth-4 years old		7	9.45%
5-10 years old		23	31.11%
11-13 years old		8	10.81%
14-18 years old		20	27.02%
19-22 years old		11	14.86%
Race or Ethnic Group	74		100.0%
White		65	87.80%
Other		9	12.20%
Marital Status	74		100.0%
In a relationship		56	78.40%
Single		16	21.60%
Daily Responsibilities	74		100.0%
Working		58	78.40%
Not working		16	21.60%
Income	74		98.70%
≤\$49,999		16	21.62%
\$50,000 - \$99,999		19	25.67%
≥\$100,000		39	52.70%
Number of Kids in Home	74		100.0%
1		30	40.50%
2		26	35.10%
3+		18	24.30%
Current Schooling	74		100.0%
Private or public schooling		59	79.70%
Alternative school or no school		33	20.30%

Note. ¹= Participants who did not specify child's age but responded their child was 2-22; *N* = number of participants; *n* = number of participants within each category; % = percentage of participants.

fifth of children (20.30%) having attended an alternative school (home school, hospital school, no school). The rest (79.70%) attended a private or public school. Table 1 outlines participants' backgrounds demographics.

Caregivers were asked about frequency and duration of hospital stays for their children. In the last year, the majority of children (37.80%) were not hospitalized, with the least number of children (5.40%) being hospitalized three times. These groups changed when caregivers were asked about the frequency of hospital stays in the last five years. Over half of the children (51.40%) had four or more hospital stays, with the smallest group of children (8.10%) having one hospital stay. The caregivers were asked about the duration of hospital stays. When inquiring about stays ranging from one to five days, caregivers reported that approximately half of the children (48.60%) had four or

Table 2

Number of Hospitalization per Year

Number of Days	<i>N</i>	<i>n</i>	%
In the Last Year	74		100.0%
0		28	37.80%
1		22	29.70%
2		10	14.00%
3		4	5.40%
4+		10	13.5%
In the Last 5 Years	73		98.90%
0		9	12.30%
1		6	8.10%
2		11	15.00%
3		9	12.22%
4+		38	51.4%

Note. *N* = number of participants who responded about their child experiencing hospitalization; *n* = number of participants within each category; % = percentage of participants within each category.

Table 3*Length of Hospitalization by Days in the Course of Five Years*

Number of Days	<i>N</i>	<i>n</i>	%
1-5 Days	71		95.90%
0		11	14.90%
1		10	13.50%
2		8	10.80%
3		6	8.10%
4+		36	48.6%
6-10 Days	65		87.90%
0		25	33.80%
1		12	16.20%
2		5	7.00%
3		6	8.10%
4+		17	23.00%
11-20 Days	62		83.70%
0		34	45.90%
1		12	16.20%
2		6	8.00%
3		4	5.40%
4+		6	8.10%
21-30 Days	59		79.90%
0		38	51.40%
1		14	18.90%
2		1	1.40%
3		5	6.80%
4+		1	1.40%
30+ Days	60		81.20%
0		40	78.40%
1		13	21.60%
2		4	5.00%
3		1	1.40%
4+		2	2.70%

Note. *N* = number of participants who responded about their child experiencing hospitalization; *n* = number of participants within each category; % = percentage of participants within each category.

more hospital visits, and the smallest group (8.10%) had only three visits. When asked about stays ranging from 11-20 days, caregivers reported that approximately half of the children (45.90%) had zero hospital visits, and the least number of children (5.40%) reported three visits. For stays ranging from 21-30 days, the largest group of children,

roughly half, (45.90%) had zero visits, and the least number of children (5.40%) had three hospital visits. For stays that lasted over a month, more than half of the children (54.10%) had zero visits, and the least number of children (1.40%) had three visits. Tables 2 and 3 outline participants number of hospitalizations and the length of stay. (Table 2 and 3 above).

Recruitment

To recruit caregivers an email was sent to national and state disability organizations that support families of children with disabilities. This included Parent Training and Information Centers (PTIs), Community Parent Resource Centers (CPRCs), University Centers for Excellence in Developmental Disabilities (UCEDDs), Protection and Advocacy Agencies, National Association of State Directors of Developmental Disabilities Services (NASDDDS), Intellectual and Developmental Disabilities Research Center (IDDRCs), and Easter Seals.

Contact information was collected by searching the websites of national and state organizations. A total of 661 organizations were included in the recruitment process and 1,049 emails were collected of lead contacts for each organization. A total of three emails were sent to each of the identified organizations (initial recruitment and two reminders). Reminders were sent every three weeks. The recruitment lasted a total of 2 months; the survey was open between mid-July of 2022 and mid-September 2022.

Instrument

The Research Electronic Data Capture (REDCap™; Harris et al., 2009), a web-

based data collection software platform was used to create and disseminate the survey and collect anonymous participant information. Prior to recruitment, three reviewers, including two caregivers of a child with disabilities and special healthcare needs, and a university faculty with expertise in survey research, served as reviewers. Reviewers provided edits, feedback, and piloted the survey. The two caregiver reviewers only provided feedback on the survey and data were not included in the analysis. Both caregiver reviewers were parents of an individual between the ages of 28-35 whose eligibility was under multiple disabilities, and diagnosis included cerebral palsy and intellectual disabilities. Each reviewer was asked to provide edits and feedback regarding language, format, and structure of questions, and to pilot the survey to estimate the time commitment to complete the survey. Based on the feedback, nine questions were reworded for clarity before the survey was finalized, and the estimated time for completion was 15-20 minutes.

The final version of the survey included seven sections. Section 1, *demographic information*, included 12 questions that collected general information about the caregiver. Section 2, *characteristics of child or young adults*, included 11 questions related to the child's age, disability eligibility, medical diagnosis, and number and length of hospitalization (if applicable). Section 3, *schooling demographic*, included two questions related to the type of school the child or young adult attended and the grade. Section 4, *staff support*, included 20 questions about the involvement of support staff during the transition process. Section 5, *transition satisfaction*, include four questions related to caregivers' experiences as their child transitioned from the school to the hospital, and from the hospital back to the school. Section 6, *benefit of resources*, included nine

questions on caregivers' experiences as their child transitioned from the hospital to the school and the resources provided during this transition. Section 7, *views on re-entry*, included four open-ended questions to collect caregivers' perspective on the transition (addressed and unaddressed aspects), and advice that they would share with other caregivers during this transition. Branching logic was used to direct participants to certain questions based on their response.

Research Design

Descriptive qualitative and quantitative data were collected through a cross-sectional survey. The rationale for implementing a cross-sectional survey was to collect data from a hard-to-reach population (Creswell & Creswell, 2018). Participants experiences were investigated through self-report. This method of data collection was selected as it provided participants the opportunity to provide direct insight into their own point of view. Participants could be reflective and subjective when sharing their experiences (Bakhtiari et al., 2021; Praslova, 2018).

Procedure

Participants were recruited after receiving Institutional Review Board (IRB) approval from the respective institution. The survey was disseminated using snowball sampling, with the purpose of reaching as many potential and qualifying participants as possible (Parker et al., 2019). During the recruitment process, emails were received from the national or state organization (a) requesting additional information ($n = 7$), such as a jpeg version of the recruitment flyer, a pdf version of the survey questions, or IRB

approval. In these cases, information was provided soon after receiving the request; (b) request for application process ($n = 3$). In such instances, due to time constraints, an email was sent thanking the organization and letting them know that no application would be completed; and (c) request for monetary compensation for participants ($n = 1$). In this case, an email was sent to the organization indicating that no compensation would be provided as indicated on the IRB approval. Participant consent was obtained on the survey landing page. A statement was included letting participants know that they could withdraw at any point of the survey by closing the page.

Data Analysis

For data analysis purposes, operational definitions were created with the purpose of outlining and describing outcomes of this study, specific to the medical diagnosis of the child:

- (a) Chronic illness: A condition that lasts for a significant amount of time and requires ongoing monitoring and attention (Children and youth: Emergencies, 2021). Chronic illnesses usually inhibit daily functioning in one or more ways.
- (b) Genetic condition: A condition due to a change in DNA in the body. Genetic conditions may be caused by mutations, environmental factors, damage to chromosomes, or a combination of any of these factors (Healthy equity and genetic disorders, 2022).
- (c) Acquired illness or injury: A condition or disease that originates after birth and is not caused by hereditary or developmental factors (Bogart, 2014).
- (d) Congenital defect: A condition that is found in the heart and is present at birth (Congenital heart defects, 2023). They often alter the structure or function of the

heart. A congenital disability is an often-inherited medical condition that occurs at or before birth (Bogart, 2014).

(e) Acute illness: A condition that is often sudden in onset and can vary in type. They are a disease or period of sickness affecting your body or mind (Hadjiliadis, 2022).

(f) Acute injury: A condition that is sudden in onset and variable in type, and is physical damaging of the body (Hadjiliadis, 2022).

Under the child's demographic following IDEA's part C and part B guidelines (IDEA sec. 20 U.S.C. 1412. Part B & C, 2004), grade-level or age correspondences were defined. Data were grouped into (a) early childhood, which included children between the ages of birth-4 years; (b) elementary school, which was comprised of children from kindergarten up to 5th grade (5-10 years); (c) middle school, which included children from 6th to 8th grade (11-13 years); (d) high school, which incorporate children from 9th to 12th grade (14-18 years); and (e) transition, which encompass children from 9th to 12th grade (19-22 years). The rationale for these categories was to determine potential similarities and differences across grades or ages.

After data collection, participants responses were assigned numerical code. Anonymous quantitative data were exported from REDCap™ to Statistical Package for Social Sciences (SPSS; version 29.0), and anonymous qualitative data were exported to an Excel spreadsheet. Three psychometric considerations for survey studies were conducted: (a) reliability, by calculating Pearson's Product correlation and Cronbach's alpha for each of the survey questions; (b) validity, through factor analysis; and (c) usability by validating the survey based on practitioners' and experts' opinions (Marsden

& Wright, 2010; Newman & McNeil, 1998). Participant response analyses included thematic analysis for open ended survey responses of question one and two. The first author read through all responses, developing operational definitions and examples based on the content of responses. This allowed for authors to categorize caregiver responses into specific themes. Descriptive statistics and correlates of the caregivers' experiences and recommendations. These were conducted by comparing themes to participant demographics using Fisher's Exact Tests. Coding reliability was conducted by a second coder. The first 30% of the responses for RQ1 ($n = 22$) and for RQ2 ($n = 23$) were coded together by coder one and two. The remaining responses (RQ1, $n = 49$; RQ2, $n = 50$) were coded by the first coder. After coding was completed, a random selection of 30% for each research question (RQ1, $n = 22$; RQ2, $n = 22$) were coded by the second coder for reliability purposes. Cohen's kappa (1960) was used to calculate reliability for both questions, with substantial agreement across all themes for RQ1 ($k = 0.62$) and for RQ2 ($k = 0.66$). When disagreements occurred, the two coders discussed the case before assigning each response to its appropriate theme. For RQ1, one person responded only to this question, while three people only responded to RQ2. The remaining 70 caregivers answered both open-ended questions.

CHAPTER III

RESULTS

The number of children ages three to 21 who are served under IDEA in the United States has increased significantly over the past 10 years (National Center for Education Statistics, 2022). Unlike the increase in number of children with disabilities, the number of hospital stays for children and adolescents has decreased over time (Shaw & McCabe, 2008; Sturm & Bao, 2000). In fact, between 2004 and 2019, the number and rate of inpatient stays for children decreased by 20 percent (Weiss et al., 2022). It has been suggested that the decrease may be due to the shift to outpatient services, as well as increased pediatric care coordination (Weiss et al., 2022). Furthermore, children with special healthcare needs are also living longer, as hospital care for these children has improved (Cohen & Patel, 2014). Because of this, children are transitioning back to their school settings more quickly after hospitalizations, often putting immense stress on the caregivers as they support their child in the transition (Shaw & McCabe, 2008; Sturm & Bao, 2000; Todis et al., 2018). As such, knowledgeable school personnel have had to step up to ease this transition for caregivers by advocating for their students with disabilities and special healthcare needs (Andersson et al., 2016).

Positive Outcomes During the Re-entry (RQ1)

Four overarching themes emerged from caregivers' responses of RQ2, including 'needs met' (20.62%), 'school support' (28.87%), 'service provisions' (19.59%), and 'no steps were taken to support the family' (18.56%). The remaining (12.37%) responses suggested that this 'experience did not apply' to the family. A total of 54 caregiver responses were coded for just one theme, while 17 responses were coded across multiple themes. The 'needs met' theme is defined as the needs of the family and child that were met by any school member/school system during the transition back into the school. 'School support' is any support provided by the school in general, either a specific school personnel or the school environment in general adapted to support the child as they come back to school. 'Service provisions' is defined as any resources or services offered by the school to the family or child as they transition back in. These may be related services, home-bound resources, or support as they transition to home-bound, or general flexibility for the family. The 'no steps were taken to support the family' theme was coded when there were no structures of communication attempts to help with the families transition back to school. Finally, the 'experience did not apply' theme is defined by the participant providing a response that was not applicable to the research question. (See table 4).

No significant influencing factors were found within the 'needs met' theme nor the 'service provisions' theme. A common statement made by caregivers within these can be best described by Participant 187 who indicated, when asked what was best addressed by the school, "her specific health needs, very aware of any concerns to let me know about;" and Participant 145's who indicated that what the school best addressed was "adjustments to IEP to make transition easier and routine for all that work with my

Table 4

Operational Definitions and Examples of Participant Responses for Positive Experiences During Re-entry Back to School.

Theme	Operational Definition	Responses		Example Responses
		<i>n</i>	%	
Needs met	The needs of the family and child were met by any school member/school system during the transition back into the school.	20	20.62%	<i>“His current medical state and how to best handle an acute asthma attack. Training all team members who supported Matt.”</i>
School support	Any support provided by the school in general, either a specific school personnel or the school environment in general adapted to support the child as they come back to school.	28	28.87%	<i>“Special Ed teacher, paraprofessional and school nurse listened and implemented updated care plans or health procedures as trained by parent.”</i>
Service provisions	Any resources or services offered by the school to the family or child as they transition back in. These may be related services, home-bound resources, or support as they transition to home-bound, or general flexibility for the family.	19	19.59%	<i>“The school was very clear that we could have as much flexibility as we needed upon re-entry.”</i>
No steps were taken to support family	Families felt unsupported by the school or school district. There were no structures of communication attempts to help with the families transition back to school.	18	18.56%	<i>“Nothing whatsoever. Our experience with the transition from the hospital back to school was a nightmare with the school showing zero empathy and offering almost zero support at all.”</i>
Experience did not apply	When the participant provided a response that was not applicable to the research question.	12	12.37%	<i>“My child was younger than 3-years when discharged from the hospital, so the school district was not involved.”</i>

Note. % = percentage of participants; *n* = number of participants.

child.” However, in the ‘school support’ theme, there were significant influence factors within the days of hospitalization for 21–30-day hospitalizations, $X^2(4, n = 17) = 7.794$, $p = .009$, with 23.94% of caregivers in this demographic ($n = 17$) reporting that they felt school personnel provided support to their family. Significant influences were also seen for hospitalizations longer than a month, $X^2(4, n = 18) = 10.268$, $p = .036$, with 25.35% of caregivers ($n = 18$) feeling that they were supported by school staff. These responses showed the increase satisfaction from caregivers whose children had longer hospital stays. Meaning that schools provided more supports for children who transitioned back from longer-term hospital stays. An example of responses within this theme included “my child's former kindergarten teacher went above and beyond to try and get me in touch with resources and the correct people” (Participant 69).

Significant influencing factors were found within the ‘no steps were taken to support the family’ theme for schooling type, $X^2(1, n = 19) = 15.453$, $p = <.001$, as 26.75% ($n = 19$) of caregivers fell under this theme. For example, caregivers whose children attended alternative schooling (i.e., home school, hospital school, no school) ($n = 10$; 14.08%) reported greater feelings of neglect from their child’s school during the transition, compared to caregivers of children who attend private or public school. Also, within this theme, income showed significant influence, $X^2(2, n = 19) = 6.003$, $p = .050$, with 11.27% ($n = 8$) of the caregivers coded into this theme, reported an income of \$49,999 or less. The total number of caregivers who felt unsupported by the school was 26.76% ($n = 19$) for income demographics.

The ‘no steps were taken to support the family’ theme also showed significant influence in marital status, $X^2(1, n = 19) = 5.691$, $p = .017$, as 15.49% ($n = 11$) of

caregivers in a relationship felt that there were not steps taken to support their family during the transition compared to single parents ($n = 8$; 11.27%). While the percentage of single parents was relatively small compared to the total respondents, the number of single caregivers in this survey totaled to 16, and 50% of them ($n = 8$), felt that the school did not support their family. This highlights the experience of single-caregiver families feeling that their family's needs were not met by the school, Fisher's Exact Test, $p = .026$. An example of responses within this theme included, "The school didn't care and frequently argued with me over the doctor's orders on medications or days off required to recover before he could return to school. For his migraines, they would do absolutely nothing" (participant 30). (See tables 5 and 6).

Negative Outcomes During the Re-entry (RQ2)

Four overarching themes emerged from caregiver responses of RQ2 including, 'needs not met' (68.52%), 'ineffective transition process' (31.48%), 'lack of knowledgeable staff' (27.78%), and 'all steps were taken to support family' (29.63%). The remaining (7.41%) responses suggested that this 'experience did not apply' to the family. A total of 54 responses were coded for one theme, while 15 were coded across multiple themes. The 'needs not met' theme can be defined as the needs of the family and child that were not met by any school member/school system during the transition back into the school. 'Ineffective transition process' is when the school did not facilitate a smooth transition because they did not provide materials and information to the family and/or the transition was unorganized and chaotic. The them 'lack of knowledgeable staff' is defined by the school staff missing opportunities to support the family, provide

Table 5

Comparisons of Participant and Child Demographics to Emerging Themes for Positive Experiences During Re-entry Back to School.

Demographics	N	Emerging Themes											
		Needs Met (20.62%; n = 20)			School Support (28.87%; n = 28)			Service Provisions (19.59%; n = 19)			No Steps Taken (18.56%; n = 18)		
		X^2	<i>p</i>	P^2	X^2	<i>p</i>	P^2	X^2	<i>p</i>	P^2	X^2	<i>p</i>	P^2
Relationship to child	71	1.064	0.302	0.566	1.316	0.251	0.550	0.769	0.380	1.000	2.545	0.111	0.173
Parent age	71	2.966	0.230		1.525	0.467		0.126	0.939		3.282	0.194	
Child age	71	5.105	0.403		6.106	0.296		5.666	0.340		7.351	0.196	
Race or ethnic group	71	0.703	0.402	0.409	0.272	0.602	0.686	0.297	0.586	1.00	0.935	0.333	0.673
Marital status	71	1.803	0.179	0.327	1.163	0.281	0.362	0.364	0.546	0.722	5.691	0.017*	0.026*
Daily responsibilities	71	0.380	0.54	0.531	0.028	0.868	1.00	0.012	0.912	1.00	0.033	0.857	1.00
Income	71	0.748	0.688		1.393	0.498		2.884	0.236		6.003	0.050*	
# of kids in home	71	2.859	0.24		1.662	0.436		1.352	0.509		0.652	0.772	
Current schooling	71	1.452	0.23		0.838	0.36		2.046	0.153		15.453	<.001*	

Note. * = significant at $p < .05$; # = number; P^2 = p value of Fisher's Exact test; N = number of participants; n = number of participants.

Table 6*Comparisons of Participants' Hospitalization Demographics for Emerging Themes in Positive Experiences During Re-entry*

Hospitalization	N	Emerging Themes							
		Needs Met (20.62%; n = 20)		School Support (28.87%; n = 28)		Service Provisions (19.59%; n = 19)		No Steps Taken (18.56%; n = 18)	
		X^2	<i>p</i>	X^2	<i>p</i>	X^2	<i>p</i>	X^2	<i>p</i>
In the last year	71	2.80	0.592	2.746	0.601	2.624	0.623	0.438	0.979
In the last 5 years	71	1.10	0.894	0.755	0.944	2.534	0.639	1.847	0.764
For 1-5 days	71	3.57	0.468	3.031	0.553	3.351	0.501	6.417	0.17
For 6-10 days	71	6.95	0.139	3.76	0.439	1.261	0.868	5.262	0.261
For 11-20 days	71	2.97	0.562	9.385	0.052	5.702	0.223	5.203	0.267
For 21-30 days	71	0.91	0.924	7.794	0.009*	5.675	0.225	4.78	0.311
≥ a month	71	5.24	0.264	10.268	0.036*	8.157	0.086	3.477	0.481

Note. * = significant at $p < .05$; N = number of participants; n = number of participants.

information, or provide care to successfully facilitate a transition back to school. ‘All steps were taken to support the family’ is when the school met all needs of the child and family. Finally, the ‘experience did not apply’ theme was coded for when the participant provided a response that was not applicable to the research question. (See table 7 below).

No significant influencing factors were found within the ‘ineffective transition process’ theme, ‘lack of knowledgeable staff’, nor the ‘all steps were taken to support the family’ theme. A common statement made by caregivers within these can be best described by participant 39 who indicated when asked about what was unaddressed by the school, “the school did almost nothing for my child during this difficult time”, and participant 27’s who indicated what was unaddressed was “educating school staff about my son's needs/changes in his needs”. Finally, “...we have a good relationship and that helped the transition” is said to be what helped the family, according to participant 214.

Significant influencing factors were found within the ‘needs not met’ theme, specifically within days of hospitalization in the last year, $X^2(4, n = 31) = 12.71, p = .013$. Caregivers whose child had a hospital stay in the last year and felt that their family’s needs were not met by the school, totaled to 42.47% ($n = 31$). For example, caregivers whose children did not have a stay in the hospital over the past year ($n = 12$; 16.44%) felt that the school did not meet the needs of their child as they transitioned back to school. A common statement made by caregivers in this theme can be described by participant 30, who indicated when asked about what was unaddressed by the school “they didn't care about anything that would prevent reoccurrences and would not give him his medications when needed because he is non-verbal and could not tell them that he needed the medications”. (See tables 8 and 9).

Table 7*Operational Definitions and Examples of Participant Responses for Negative Experiences During Re-entry Back to School.*

Theme	Operational definition	Responses		Example Responses
		<i>n</i>	%	
Needs not met	The needs of the family and child were not met by any school member/school system during the transition back into the school.	37	41.57%	<i>“The social aspect of missing out on holiday parties and Reentry into school after several weeks of missed instruction and group learning/community.”</i>
Ineffective transition process	The school did not facilitate a smooth transition because they did not provide materials and information to the family and/or the transition was unorganized and chaotic.	17	19.10%	<i>“Not enough training for parents. At diagnosis (3yrs old) and/first signs of nystagmus (newborn in hospital) there should have been trauma therapy available....”</i>
Lack of knowledgeable staff	The school staff missed opportunities to support the family, provide information, or provide care to successfully facilitate a transition back to school.	15	16.85%	<i>“The school did not fully understand the accommodations. The VI tried her very best to help and give the information out to the school, but they were less than helpful and pushed back on accommodations.”</i>
All steps were taken to support family	There was nothing unaddressed during the transition, the school met all needs of the family.	16	17.98%	<i>“Nothing really my daughter's school is and has been very on point all the time.”</i>
Experience did not apply	When the participant provided a response that was not applicable to the research question.	4	4.49%	<i>“He has hospitalized during summer break.”</i>

Note. % = percentage of participants; *n* = number of participants.

Table 8*Comparisons of Participant and Child Demographics to Emerging Themes for Negative Experiences During Re-entry Back to School.*

Demographics	N	Emerging Themes											
		Needs Not Met (68.52%; n = 37)			Ineffective Transition Process (31.48%; n = 17)			Lack of Knowledge Staff (27.78%; n = 15)			All Steps Taken (29.63%; n = 16)		
		X^2	<i>p</i>	P^2	X^2	<i>p</i>	P^2	X^2	<i>p</i>	P^2	X^2	<i>p</i>	P^2
Relationship to child	73	2.309	0.129	0.254	0.238	0.625	0.530	0.742	0.389	1.000	3.295	0.069	0.133
Parent age	73	4.508	0.105		0.827	0.661		0.788	0.674		0.181	0.913	
Child age	73	8.098	0.151		5.238	0.388		8.223	0.144		6.704	0.244	
Race or ethnic group	73	0.350	0.554	0.724	0.701	0.403	0.673	2.436	0.119	0.192	2.572	0.109	0.199
Marital status	73	0.476	0.490	0.572	1.062	0.303	0.496	0.448	0.503	0.491	0.236	0.627	0.748
Daily responsibilities	73	2.558	0.110	0.154	0.120	0.729	1.000	0.002	0.961	1.000	2.317	0.118	0.180
Income	73	2.882	0.237		1.094	0.579		1.417	0.492		2.495	0.287	
# of kids in home	73	2.529	0.282		4.375	0.112		1.272	0.529		1.350	0.509	
Current schooling	73	0.136	0.712		1.438	0.231		0.008	0.928		0.114	0.735	

Note. # = number; P^2 = p value of Fisher's Exact test; N = number of participants; n = number of participants.

Table 9*Comparisons of Participants' Hospitalization Demographics for Emerging Themes in Negative Experiences During Re-entry.*

Hospitalization	N	Emerging Themes							
		Needs Not Met (68.52%; n = 37)		Ineffective Transition Process (31.48%; n = 17)		Lack of Knowledge Staff (27.78%; n = 15)		All Steps Taken (29.63%; n = 16)	
		X^2	<i>p</i>	X^2	<i>p</i>	X^2	<i>p</i>	X^2	<i>p</i>
In the Last Year	73	12.710	0.013*	6.742	0.150	5.063	0.281	6.126	0.190
In the Last 5 Years	73	6.309	0.177	1.966	0.742	1.564	0.815	4.503	0.342
For 1-5 Days	73	1.607	0.808	2.901	0.574	5.313	0.257	3.236	0.519
For 6-10 Days	73	2.991	0.559	2.468	0.650	1.805	0.772	7.330	0.119
For 11-20 Days	73	9.360	0.053	3.401	0.493	4.395	0.355	5.441	0.245
For 21-30 Days	73	6.369	0.173	2.898	0.575	2.898	0.575	2.479	0.648
≥ a month	73	6.770	0.148	3.925	0.416	2.623	0.623	1.862	0.761

Note. * = significant at $p < .05$; N = number of participants; n = number of participants.

CHAPTER IV

DISCUSSION

This study aimed to explore the perspectives of caregivers of children with disabilities and special healthcare needs during their transition from hospital to school. The goal was to identify common experiences and provide recommendations for future practices. The findings indicated that the majority (82.02%) of caregivers and children did not receive adequate support from the school. Specifically, in response to the question on what the school did well during the transition (RQ1), only 20.62% of caregivers reported that their child's needs were met, 28.87% felt that school personnel were supportive, and 19.59% felt that there were proper service provisions to assist with the transition. In contrast, when asked about what was lacking from the school during the transition (RQ2), 41.57% of parents felt that their child's needs were not met, 19.10% of caregivers felt that the transition process was ineffective, and 16.85% of caregivers felt that there was a lack of knowledgeable school staff supporting their family.

School Support and Ineffective Transitions

The responses of caregivers highlighted the need for schools to provide support to children with disabilities and special healthcare needs. This can be achieved through the creation of an effective transition process, which includes equipping the transition team with knowledge and resources to advocate for the family's needs (Andersson et al., 2016; Todis et al., 2018). However, approximately one-fifth of the caregivers (21.92%) felt that the transition process was ineffective, and a similar percentage

(19.18%) felt that there was a general lack of knowledgeable school personnel who could aid in the transition.

To address these issues, we recommend that schools provide an effective transition program and identify key resources for this process to support caregivers and children with disabilities and special healthcare needs. It's important to note that the supports provided during the transition should be based on the needs of the child as they return to school, not on the length of hospitalization. Caregivers must often advocate for accommodations for their child because school personnel lack knowledge and confidence to serve the child (Andersson et al., 2016).

The length of time a child misses' school due to hospitalization affects the level of support provided by school personnel. Caregivers whose children experienced longer hospitalizations reported feeling greater support from their child's school. For hospital stays of 21-30 days, 23.94% of caregivers described a supportive school environment, and 25.25% of caregivers whose children experienced hospital stays of longer than a month reported the same. This may be because a greater number of missed school days is often cause for school concern, as the child is at greater risk of falling behind academically (Carlton et al., 2021; Vanneste et al., 2016).

Overall, caregivers felt that some school personnel, including the school nurse, special education teachers, and guidance counselors, were supportive during their child's transition back to school. With proper training on serving children with disabilities and special healthcare needs as they transition back from the hospital, school personnel can reduce barriers in the transition for the entire family (Aviles & Andersson, 2006), especially when prolonged hospital stays have caused the student to fall behind

academically and socially. A deliberate partnership among school personnel such as school nurses and special education teachers must be made to ensure that the student is both safe at school and making academic progress (Puffpaff et al., 2015).

Unsupported Families and Unmet Needs of Students

The findings of this study suggest that caregivers felt unsupported by their child's school during the transition due to a lack of communication attempts from both school and hospital personnel. Caregivers reported that their child's medical, physical, social emotional, and academic needs were not being met by the school personnel. This is consistent with the findings of Todis et al. (2018), who found that parent satisfaction with the return to school depended on how responsive they felt teachers were to their child's needs and how closely school staff followed recommended practices. Educators who had little experience or training in serving students with disabilities and special healthcare needs made it particularly difficult for parents to agree with their educational approaches.

Interestingly, caregivers of children who attended an alternate school (i.e., hospital-school, home-school, no school n = 10; 14.08%) reported feeling that their school did nothing to support their family during the transition, compared to those who attended private or public schooling (n = 9; 12.68%). Washburn-Moses (2011) discussed the concerns around the experience of students with disabilities in alternative settings, including the lack of data and oversight, the potential lack of services such as appropriate staffing and resources, and the lack of knowledge about quality of instruction and student outcomes on the part of program staff and leadership. These concerns may cause caregiver stress as their child transitions from the hospital setting back into an alternative

school setting. Without staff who are knowledgeable on the transition process, caregivers will be left to advocate for their child alone.

Moreover, families of only one caregiver or those who are lower income (n = 32; 43.22%) felt that their child's school did nothing to support their family during the transition back to school. Several studies indicated that there is a rise in the percentage of children living in single-parent households since the 1960s, and this is related to an increase in child poverty (Amato et al., 2015; de Lange et al., 2014). Caregivers from low-income households have reported experiences of being ignored when they shared information with teachers or administration about their child, which can in turn influence a child's educational outcomes (Amato et al., 2015; de Lange et al., 2014; Scheuerell, 2019). Many teachers expect to have a negative relationship with caregivers from low-income households (Amatea et al., 2012; Lightfoot, 2004), as there is a misconception that these caregivers care less about the wellbeing of their child. These misconceptions may be a reason that many caregivers feel unsupported by their child's school.

Caregivers whose children have been hospitalized in the last year expressed their frustration with their child's school. Almost half of the caregivers in the study felt that their child's medical, physical, social emotional, and academic needs were not being met (Cardona, 2021; Kabasakal, 2020). According to caregivers, there is a need for better planning and preparation by school personnel to improve the transition (Vanclooster et al., 2018). Communication and collaboration with the school should be immediate and clear (Vanclooster et al., 2018). Caregivers in this study spoke about feeling lonely during the transition, as the school personnel left them with unanswered questions and unmet needs. In a study conducted by Vanclooster and colleagues (2018), caregivers

were looking to their child's school to advocate for their family's needs and make the transition more manageable. School personnel should communicate often with hospital staff to stay up-to-date on the medical needs of the child. Through training and practice on supporting students with disabilities and special healthcare needs, school personnel can meet the demands of care for these children.

Practical Implications

The findings from this study highlight areas where the transition from hospital to school setting can be improved to better support caregivers. Caregivers often express a lack of support from schools during the transition process, causing them to feel uncertain and alone as they make decisions for their child. Schools have a responsibility to be involved in the transition process as much as necessary, providing clear expectations for the child upon return and resources such as informational sessions, pamphlets, and connections to professionals in the field (Blizzard et al., 2015; Edelstein et al., 2017; Hartman et al., 2015). However, many caregivers reported that schools were not invested in the transition, and gaps remained. Therefore, schools should create guidelines and select dedicated personnel who can guide caregivers through the transition process and ease their concerns (Savina et al., 2014).

Parents also describe the need for well-prepared hospital staff during the admission and long-term stays of children with disabilities in the hospital (Oulton et al., 2020). It is the responsibility of hospital personnel to seek out training on how to serve children with disabilities and special healthcare needs. Communication between the hospital and school staff is essential to ease the transition process for caregivers and their

child. Caregivers are the most vital member of the transition team and should have control over major decisions for their child. To advocate for their child's needs, they must play an active role in the transition team, communicating with hospital and school personnel to meet the needs of the child during school re-entry.

Limitations and Future Research Directions

Although this study sheds light on the transition process of children with disabilities and special health care needs, there were several limitations that need to be considered. Firstly, due to the target population, the number of potential participants was low. Moreover, the inclusion criteria only included students who would qualify under Part C and Part B of IDEA, limiting the generalizability of the findings to this specific population. The survey was also only open for two months during the summer when organizations and caregivers may have been less active in survey distribution and participation than during the school year, which may have affected the response rate.

Additionally, snowball sampling made it difficult to target the specific population required by the inclusion criteria, and future research could consider conducting interviews with caregivers of children with disabilities and special healthcare needs to elicit greater responsiveness around their views and opinions.

The participants of this survey mostly comprised White caregivers, and there was not enough representation of other racial and ethnic groups, limiting the generalizability of the findings to White families. Future research could consider a more diverse population of participants by reaching out to disability advocacy organizations that serve families of diverse racial and ethnic groups. A more diverse representation of caregivers could

provide a deeper understanding of the hospital to school transition barriers that all families experience.

Finally, the survey did not include a question asking caregivers what state or region they reside in, making it impossible to determine if differences in support may exist based on the regions of the United States. Future research could expand on the hospital to school transition process between states and districts to identify the most effective supports and implement them on a broader scale across the country. (Creswell & Creswell, 2018).

Conclusion

Given that children with special healthcare needs are living longer, a growing number of them are transitioning from hospital care to school settings. However, caregivers of children with disabilities have reported a lack of support from their child's school during these transitions. As such transitions become more common, it is essential for school personnel to learn how to support families during this process. With adequate knowledge and resources, caregivers, school personnel, and hospital personnel can collaborate to facilitate a smooth re-entry for the child. This can be achieved through communication and the appointment of a dedicated transition liaison, who can share the responsibility of the transition and alleviate the stress and isolation that parents often feel while caring for their child with disabilities and special healthcare needs. There is ample room for improvement in this process, with caregivers indicating that schools have fallen short in providing necessary support. Themes emerging from responses suggest the need for school personnel training, improved service provisions (e.g., resources, flexibility,

communication, related services), and a well-organized transition led by a transition liaison. By implementing these supports, the needs of children with disabilities and special healthcare needs transitioning from hospital to school settings can finally be met.

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