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EVALUATION OF HOSPITAL-BASED EDUCATIONAL SUPPORTS IN THE OUTPATIENT SETTING

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None.

ABSTRACT:

Objective:

Children and youth with special healthcare needs (CYSHCN) in the United States face elevated stress from managing complicated treatment regimens with school outcomes that are generally worse compared to peers. As medical care is evolving towards increasing outpatient service delivery and decreasing hospital stays, CYSHCN have limited access to inpatient educational supports. Our team aims to describe the services in the expansion of a traditional inpatient Hospital-Based School Program (HBSP) to serve outpatient hematology/oncology, pulmonology, and dialysis clinics.

Methods:

HBSP outpatient services began within outpatient hematology/oncology and pulmonology clinics followed by the dialysis clinic. Program changes focused on understanding current services, review and revision of data collection, promotion of service delivery standardization, and development of standardized hand off processes between inpatient and outpatient HBSP teachers.

Results:

Across 2016-2020, 884 patients were served. Primary diagnoses included cystic fibrosis, leukemia, brain tumor, other cancer, lymphoma, dialysis, and blood disorders. A total of 80 counties in-state were served, and patients spanned 179 school districts. Out of 445 patients, 36.4% had an existing Individualized Education Program (IEP), 51.7% had an existing 504 Plan, and 11.9% were assisted with obtaining an IEP or 504 Plan.

Conclusions:

Due to the HBSP, 884 patients received school supports. This showed that individuals who did have school supports received advocacy and a change in school services engagement with this HBSP. To our knowledge, this is one of the first studies to describe patient characteristics of individuals seen by an HBSP in outpatient clinics and the subsequent educational supports.

MANUSCRIPT:

INTRODUCTION

There are more than 13.6 million Children and Youth with Special Healthcare Needs (CYSHCN) in the United States (U.S.)(1) facing chronic and systemic stress from complicated treatment regimens and school outcomes that are generally worse compared to peers.(2) CYSHCN who also experience poverty(3) or are in racial minority groups(4) face additional, disproportionate burden related to their academics.(5) Lengthy periods of absenteeism have been linked to poorer academic performance, impaired social well-being, and grade retention(6, 7) with decreased instruction time and increased rates of school dropout prior to graduation.(8) These factors necessitate educational supports (e.g., Individualized Education Program [IEP], Section 504 Plan [504], medical homebound) for CYSHCN tailored to their needs. Variable school services have been described in the literature for this population including homebound instruction, flexible scheduling, differentiated instruction, school re-entry plans, in-service training for teachers and staff, communication with key stakeholders (i.e., teachers, caregivers, and medical professionals), and formalized school supports through IEP or 504.(9-11)

Communication and collaboration across schools, medical facilities, and families may be one of the keys to optimizing school services for CYSHCN, such as providing knowledge about diagnosis.(12) This is an area where Hospital-Based School Programs (HBSP) have been developed for inpatient CYSHCN and standardized recommendations for best practice are emerging,(13, 14) though currently HBSP show significant variability in construction and function.(15) As medical care is evolving towards increasing outpatient service delivery and decreasing hospital stays, CYSHCN undergoing care in the outpatient setting have limited access to equivalent educational supports (e.g., teachers, psychologists) compared to inpatients with the same or similar medical needs.(16)

Our team seeks to describe the services and initial impact in the expansion of a traditional inpatient HBSP to serve particularly vulnerable outpatient populations impacted specifically by diagnoses of cancer, cystic fibrosis (CF), or undergoing dialysis in outpatient clinical settings. These three groups are well described in terms of medical care movement into the outpatient setting(17-19), but little is known about the associated service delivery around school support. Initial outpatient clinical service data from the HBSP of a single children's hospital is described in the present study, focusing on programmatic adaptation serving these CYSHCN. To our knowledge, guidelines for running an outpatient HBSP have not yet been published.

The described HBSP was founded in 1924 with inpatient service delivery only. Outpatient specific HBSP services began in 2016 with a single teacher serving outpatient hematology/oncology (H/O) and pulmonology clinics. The primary patients receiving HBSP support were those impacted by CF, leukemia, or brain tumors in those settings. CYSHCN with cancer or CF have been identified as particularly vulnerable populations in relation to school experiences.(2) Dialysis clinic joined the outpatient service line in 2018, having previously been a part of the inpatient HBSP. By the end of the 2019-2020 school year, the outpatient HBSP team had grown to four full-time teachers providing services across these CF, H/O, and dialysis clinics. All teachers in the HBSP hold appropriate state licensing and are fully funded by the hospital through a combination of state Department of Education (DOE) and donor monies. All HBSP services are provided at no cost and were not billed to their insurance. Outpatient services

follow the state school calendar year with closures for federal holidays, weekends, and winter/summer breaks.

The primary focus of care in the outpatient HBSP setting is educational advocacy. Educational advocacy services include liaising between medical-educational settings to translate any medical recommendations to the educational setting, recommending classroom supports, advocating for school re-entry services, and educating school personnel and peers about disease course and school life impact. Re-entry work provided by HBSP focuses on communication of the patient's post-discharge needs to the school of record with information on supportive accommodations based on the patient's medical condition(s) as it impacts education access. Patients in the dialysis clinic additionally received direct instruction due to the burden of school absenteeism to complete academic assignments, lessons, and testing sent by their school of record. HBSP teachers also developed academic remediation materials in specific cases where patients were unable to complete these due to medical needs. Engagement with the HBSP required consent from the patient's legal guardian.

Patients in the H/O or CF clinics were connected to the outpatient HBSP by: 1) a provider during the clinic appointment; 2) the medical team during the bi-weekly staff meetings; 3) an inpatient team handoff post-hospitalization; or 4) family request based on prior knowledge of the HBSP. These consult methods resulted in highly variable access for patients and families in these clinics. All school-aged patients in dialysis clinic received automatic consultation and subsequent direct instruction (60 minutes one-on-one) during each dialysis session. For additional details on the process for referral, services provided during their outpatient care, and services provided after discharge from outpatient care (**Figure 1**).

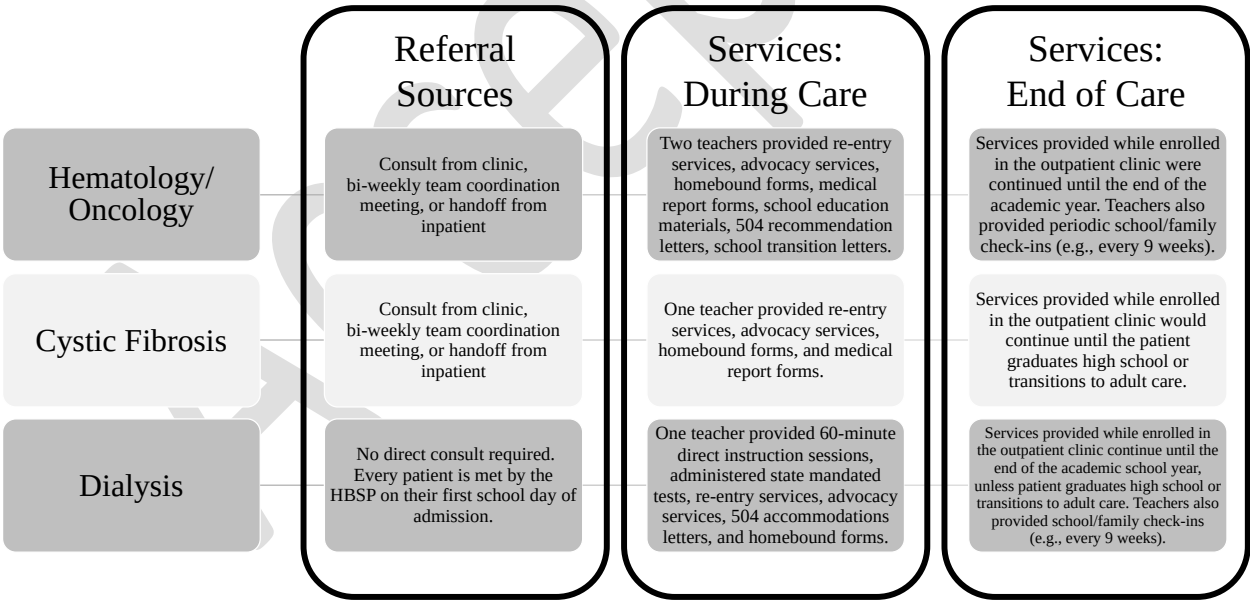

Figure 1. Service overview for the outpatient HBSP from referral to discharge from care.

Services provided were highly variable across the 2016-2017 to 2019-2020 academic years primarily due to staffing growth. Data were initially collected strictly for funding-based reporting, following the same requirements as the inpatient HBSP team(14), as set forth by the DOE. Variables collected included school demographics consisting of the county and specific

location, school name, school district, and school type (i.e. public, charter, etc.). Patient information captured included academic level (i.e., grade), frequency of engagement with the HBSP through consultations for educational advocacy (i.e., initial school consult, hospital follow up consult, school plan support, etc.), and direct instruction sessions. Forms or paperwork sent to schools by the HBSP were tracked, including recommendations for interventions (e.g. IEP, homebound), state testing exemption letters, and medication report forms. Finally, school meetings attended by HBSP personnel were tracked, such as but not limited to IEP, 504, or school re-entry meetings. Consent records were stored per The Family Educational Rights and Privacy Act (20 U.S.C. § 1232g; 34 CFR Part 99, U.S. DOE).

This study was IRB approved through the associated university system. Initial data analysis demonstrated that data reflected only the last contact between HBSP and patient. Previous information on HBSP and patient contacts were not kept in this period and as such work across the academic year was not tracked. Data within an academic year (e.g. 2016-2017) reflected the final educational information only (e.g. presence of an IEP). Additionally, information was not tracked across years for returning patients or across inpatient-outpatient medical care.

HBSP teachers entered data during the 2016-2017, 2017-2018, 2018-2019, and 2019-2020 academic years. Of note, during the 2019-2020 academic year, data were not entered during the final quarter due to COVID-19 related school closures. Not all patients had complete data available due to organic programmatic development during the initial period. Patient diagnosis, school demographics, and HBSP services to assist with re-entry are described here. Data were de-identified for analysis and protected health information for the patient was removed. Data were analyzed to produce descriptive statistics. Specific parameters of the school systems served by HBSP including school demographics for public schools and poverty classification (as determined via use of free/reduced-price lunch(20)) were likewise obtained through the state DOE records freely available through the state-maintained website. The poverty level of the school of record was based on the percentile of students across the student body receiving free/reduced lunch against the overall school population, grouped into quartiles for reporting. School rurality was based on the state DOE report for the district and school of record in declining size/urbanicity as: city, suburban, town, and rural.

RESULTS

Across the initial 2016-2019 academic years, 884 patients were served with an average of 221 (*SD*=59.40) patients served per year. From the 2016-2017 academic school year, the HBSP program saw an 80% growth rate in patients served by the 2019-2020 academic school year (**Figure 2**).

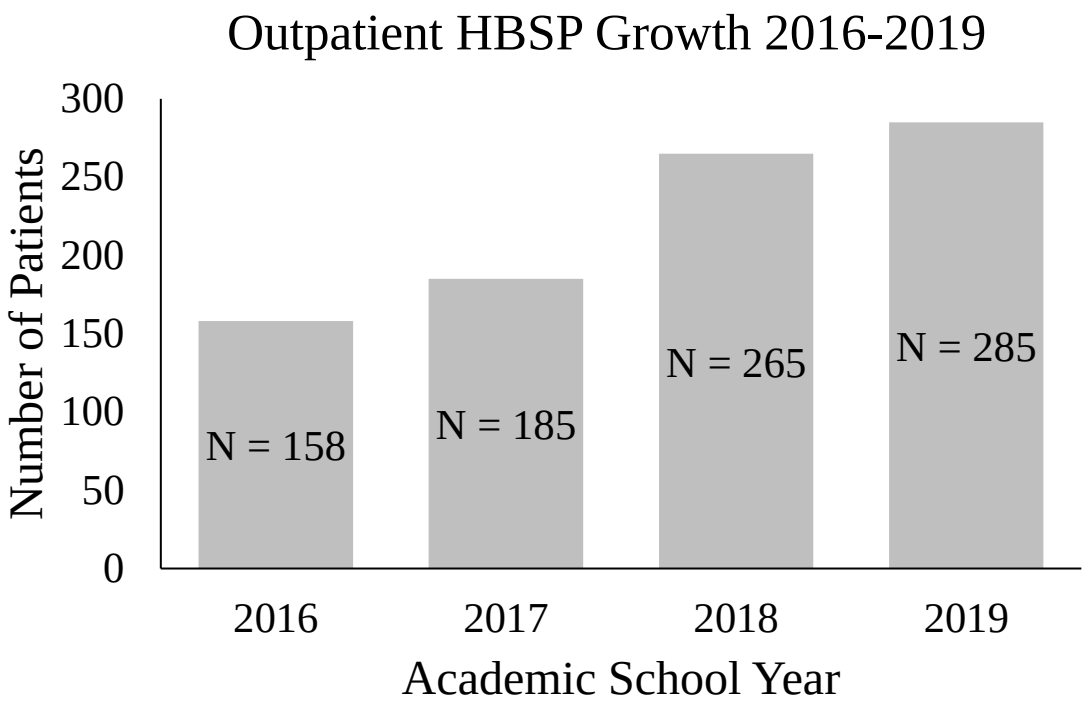

Figure 2. Outpatient HBSP growth from the initiation of the program in the 2016-2017 academic school year to the 2019-2020 academic school year.

The program primarily served three outpatient hospital associated clinics: HO (59.5%), pulmonology (36%), and dialysis (4.5%). See **Table 1** for patient diagnostic breakdown and school demographic information.

Table 1. Participant characteristics and school demographics across the 2016-2017 through 2019-2020 academic years.

	Percentage (*n*)				
Characteristics	**All Years**	**2016-2017**	**2017-2018**	**2018-2019**	**2019-2020**
Patient Primary Diagnosis (*N=879)*					
Cystic Fibrosis	36% (318)	39.5% (62)	30.2% (55)	30.6% (78)	43.2% (123)
Leukemia	24.8% (219)	14.6% (23)	28.6% (52)	29.8% (76)	23.9% (68)
Brain tumor	16.9% (149)	27.4% (43)	20.3% (37)	16.1% (41)	9.8% (28)
Other cancer	8.5% (75)	6.4% (10)	6.0% (11)	10.2% (26)	9.8% (28)
Lymphoma	5.1% (45)	2.5% (4)	7.1% (13)	5.5% (14)	4.9% (14)
Dialysis	4.4% (39)	--	4.9% (9)	5.5% (14)	5.6% (16)

Blood Disorders	2.5% (22)	6.4% (10)	1.6% (3)	1.6% (4)	1.8% (5)
Other medical condition/procedure[a]	0.8% (7)	1.3% (2)	1.1% (2)	0.4% (1)	0.7% (2)
Other pulmonary disorders[b]	0.6% (5)	1.9% (3)	--	0.4% (1)	0.4% (1)
School Location (*N=583)*					
Urban	32.4% (189)	--	35.0% (50)	34.3% (73)	29.1% (66)
Rural	28.6% (167)	--	28.0% (40)	28.6% (61)	29.1% (66)
Suburban	25.2% (147)	--	26.6% (38)	23.0% (49)	26.4% (60)
Town	13.7% (80)	--	10.5% (15)	14.1% (30)	15.4% (35)
School Poverty Level (*N=620)*					
High	12.4% (77)	--	17.4% (27)	14.1% (32)	7.6% (18)
Mid-high	35.0% (217)	--	31.0% (48)	34.8% (79)	37.8% (90)
Mid-low	37.9% (235)	--	34.2% (53)	38.3% (87)	39.9% (95)
Low	14.7% (91)	--	17.4% (27)	12.8% (29)	14.7% (35)
Grade (*N=858)*					
Pre-K/Kindergarten	12.6% (108)	8.8% (13)	11.6% (21)	15.4% (39)	12.6% (35)
Elementary (1st-5th grade)	34.0% (292)	33.3% (49)	33.7% (61)	32.8% (83)	35.7% (99)
Middle School (6th-8th grade)	23.1% (198)	26.5% (39)	24.3% (44)	22.5% (57)	20.9% (58)
High School (9th-12th grade)	28.9% (248)	31.3% (46)	29.8% (54)	28.5% (72)	27.4% (76)
Graduated Highschool	0.2% (2)	--	0.6% (1)	--	0.4% (1)
Attending College	1.2% (10)	--	--	0.8% (2)	2.9% (8)

Note. Consistent with previous research, [25] we used the percent of enrolled students who were eligible for free/reduced-price lunch as a proxy for school poverty level, and schools were grouped into 4 categories: low-poverty (0-24.9%), mid-low (25-49.9%), mid-high (50-74.9%), and high-poverty (75-100%). [a]Other medical condition/procedure included: Chediak-Higashi Syndrome and bone marrow transplant, craniotomy, hemophagocytic lymphohistiocytosis, and

juvenile xanthogranuloma. [b]Other pulmonary disorders included asthma, pulmonary embolism, and tracheostomy.

Primary diagnoses served included: CF (36.0%), leukemia (24.8%), brain tumor (16.9%), other cancer (8.5%), lymphoma (5.1%), dialysis (4.4%), and blood disorders (2.5%). Only 10 students were from outside of the state where the HBSP and hospital were located. A total of 80 (*N*=682) counties (86.95%) in-state were served (**Figure 3A**). Patients spanned 179 of the state's 291 school districts (*N*=700) with 157 enrolled in public schools (54.14%) and 23 enrolled in nonpublic schools (**Figure 3B**).

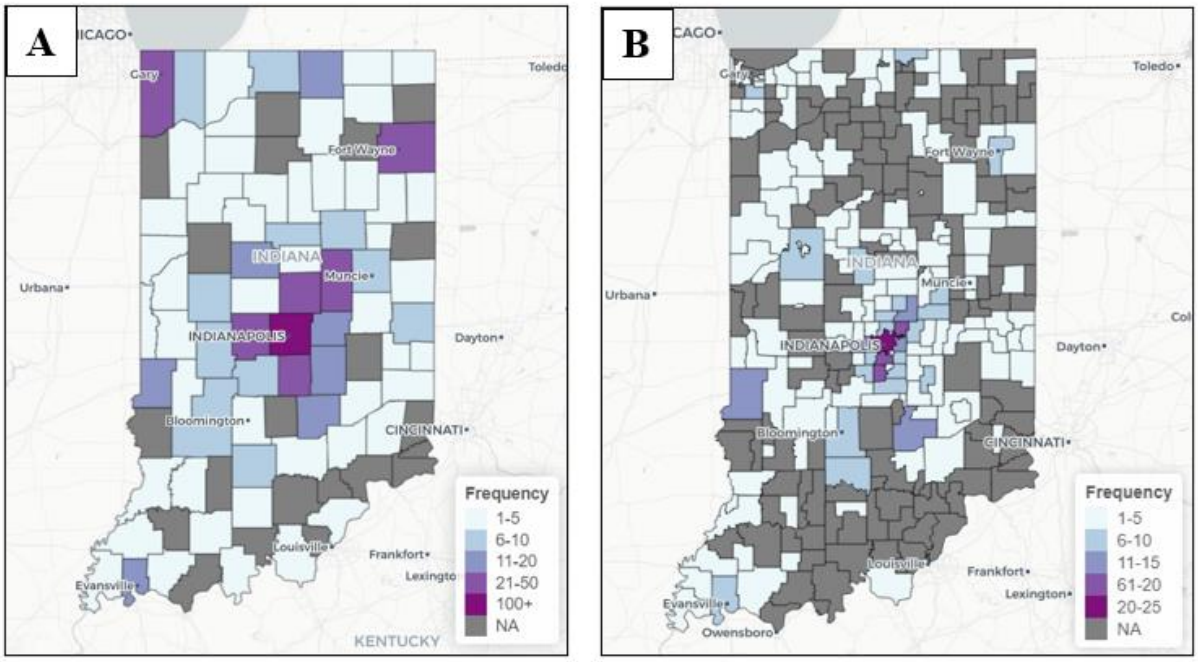

Figure 3. Number of patients served through HBSP by (A) county and (B) school district across the state.

The majority of patients served resided in urban areas (32.4%) in comparison to the suburban areas (25.2%), rural areas (28.6%), and towns (13.7%) (*N*=583). The majority of patients served lived in mid-high (37.9%) to low-high (35%) poverty in comparison to high (14.7%) and low (12.4%) poverty (*N*=620) as based on the free/reduced lunch statistics at the school of record.

Out of 445 patients, 36.4% had an existing IEP and 51.7% had an existing 504 at the time of initial engagement with the HBSP for that year. However, 11.9% were assisted with obtaining or initiating an IEP or 504 through their local school district. The top five most commonly served grades included: 10th (*N*=79), 9th (*N*=79), 1st (*N*=77), kindergarten (*N*=70), and 8th (*N*=68).

DISCUSSION

CYSHCN represent a growing population in the U.S. with unique medical and academic needs.(1, 2, 6, 7) To promote childhood health for CYSHCN, patients need support in achieving their personal potential across those domains.(21) While HBSPs have developed to support the academic needs of inpatient CYSHCN,(13-15) a number of chronic medical conditions are being increasingly managed in the outpatient setting(17-19) where little is known about the supports that are most necessary, particularly for individuals with cancer, CF, or receiving dialysis. With these medical care delivery shifts, novel service delivery in outpatient settings is needed to meet patient academic needs. In the context of the unique needs of these subgroups of CYSHCN with cancer, CF, or receiving dialysis, there is increasing recognition of the associated academic and social needs ripe to be specifically targeted.(22) As such, we described the expansion of this HBSP into the outpatient clinic setting, which has the potential to support these CYSHCN where they currently have decreased access to needed educational supports, through addition of teachers, provision of family consultation, and bridging the communication gap between school, family, and medical teams.[9]

Initial analysis of the outpatient program as it existed starting in the 2016-2017 academic year through the 2019-2020 academic year (4 school years) showed that the HBSP engaged with 884 patients in the H/O, CF, and dialysis clinics. It should be noted that the final quarter of the 2019-2020 academic year was not completed due COVID-19 related national school closures. Despite this challenge, the program demonstrated substantial growth from the 2016-2017 academic year to the 2019-2020 academic year. The distribution of the patients being cared for in these outpatient settings was statewide and represented 86.95% of counties in the state. There were 157 unique public schools with HBSP engagement through these clinical areas, representing a high level of geographic reach throughout the public sector. While not all of the impact of the HBSP can be calculated from the available data, certainly the HBSP outreach to the majority of the state allowed for an increase in advocacy and educational access for these patients.

In looking at the breakdown of impacted patients, patient and family factors related to population density and socioeconomic status are important to consider when discussing the HBSP impact as well. In looking at the areas from where these patients live, individuals in the rural areas (28.6%) and towns (13.7%) of the state represent over a third of patients impacted by the program. Additionally, the majority of patients served resided in mid-high (37.9%) to low-high (35%) poverty. Advocacy by the HBSP likely increased intervention access in their school of record in these populations, where school personnel can be presumed to have less familiarity with CYSHCN and families have fewer local specialty medical supports, leading to their need to seek care at this academic medical center. Further, when considering the impact of the program on individuals living in higher levels of poverty, we hypothesize this is an issue similar to accessing appropriate physical health services(23) where in families are disproportionately unable to access school advocacy supports, but this is a gap in the literature that needs more exploration. With the HBSP providing free services to all families and utilization of phone or video call contacts, financial and geographic barriers to service access were removed.

Individuals in high (14.7%) poverty had less engagement with the program. This may in part be attributable to the cost for travel and lodging associated with outpatient care. There is a disproportionate burden for outpatient compared to inpatient families, who may be able to room with their child or have free lodging provided through donations and other programs. While the information about changes to school supports (e.g., pre-existing IEP or 504) was not available,

11.9% of our outpatient population needed and received support with accessing an IEP/504 at their school of record after engagement with this HBSP. This is a baseline of the outpatient HBSP team's impact from available data. It is also possible that within the patients listed as having an existing IEP (36.4%) or 504 (51.7%), a percentage of those patients may have received these supports via work with the outpatient HBSP but not during a clinic appointment (e.g., parent call), working with the HBSP on inpatient, or IEP/504 supports were already in place but changes between the two were not tracked in our data. As such, the results are a description of the minimum provided supports and changes by the HBSP.

While our findings are the first to report on HBSP in outpatient settings and are promising for future work, limitations must also be considered when interpreting these results. Specifically, our project included variable data across patients, lack of specific demographic data, and limited information of the services provided by the HBSP across contacts within a single academic year or more broadly for those served across years. This was due to collection being utilized only for grant reporting requirements of the state DOE. The current information also does not offer a perspective on what interim changes may have occurred during or across academic years to school supports via the HBSP work.

Future research should expand our understanding of educational needs of CYSHN in the outpatient settings. Further, HBSP can consider training school of record staff (e.g., special education providers) to better serve this population, while bridging the gap between communication and access to educational supports across medical centers and schools. While considering next steps for the program itself, additional work could target outreach programs to schools with a history of high volume of CYSHCN or those school districts who have not been reached. Within this HBSP, increased tracking across years and between inpatient and outpatient settings will build greater understanding of the utilization of resources, necessary school supports, and even perhaps yield risk factor information around the academic needs in CYSHCN. Capture of the patient supports on initial consultation with the HBSP and the incremental changes associated with medical changes and HBSP contacts between family, school, and the medical team within and across academic years should be delineated. For instance, data tracking will show what percentage of patients are recommended at initial consult for 504 support, but go on to later recommend an IEP along with additional variables related to diagnosis change and frequency of outpatient medical consultation.

Future next steps also include standardization of services across the program. To build access and service for this unique population, patients should have access across hospitalizations and outpatient services through the school program with continuity with their HBSP personnel. Greater data collection including discrete encounters throughout a single school year as well as tracked across multiple years for CYCHSN will be appropriate to better look for patterns in service needs and program planning. Additionally, to target greater equitable distribution of care through HBSP services populations with greater needs including cumulative social determinants of health (SDOH) beyond poverty rate(24, 25) or consideration of the impact of additional adverse childhood events (ACEs) will be key areas to target research development(26) as a moderating factor within CYSHCN served in the outpatient setting. This is of particular importance due to the growing knowledge base about the role of SDOH and ACEs on medical morbidity and mortality and academic outcomes. Additional measures are needed to capture the educational impact of the work of HBSP teachers while liaising with the school of record including consideration of the various strategies used for advocacy and disease specific

educational modifications that can be then dispensed to standardize guidance. Another area of interest is to consider outcomes around the growth of school of record knowledge as to the educational needs of this population, such as the response of the school when additional students impacted by the same medical needs are identified after experience in developing intervention with this HBSP (e.g. time to support discussion, specific support type developed, etc.).

CONCLUSION

The described HBSP has grown substantially since 2016 in an attempt to address the educational needs of CYSHCN seen in outpatient settings. To the authors' knowledge, this is one of the first studies to describe the number and characteristics of patients seen by an HBSP in outpatient clinics and the subsequent educational supports developed by such a team. We build on the present knowledge of an established inpatient HBSP, further highlighting the variability across programs and the need for additional research and standardization to support the medical and academic needs of CYSHCN.[15]

Contributors Statement Page

Dr. Michelle Curtin and Dr. Debra L. Reisinger conceptualized and designed the study, designed the data collection instruments, collected data, carried out the initial analyses, drafted the initial manuscript, and critically reviewed and revised the manuscript.

Dr. Kristin Wikel conceptualized and designed the study, designed the data collection instruments, collected data, carried out the initial analyses, and drafted the initial manuscript.

Dr. Lia K. Thibodaux participated in decision making at major study points, performed study analysis, and critically reviewed and revised the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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