


Increased behavioral health needs and continued psychosocial stress among children with medical complexity and their families during the COVID-19 pandemic

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Abstract

Objective: Children with medical complexity (CMC) and their caregivers are at increased risk for multiple psychosocial stressors that can impact child and family well-being and health outcomes. During the COVID-19 pandemic, when access to supports diminished, psychosocial screening and integrated behavioral health (IBH) services in the primary care setting were crucial in identifying and addressing the unique needs of this population

Methods: Universal screening to identify psychosocial needs was implemented in a primary care clinic for CMC that includes IBH services. Data on the prevalence of psychosocial screening and IBH services for young children and their caregivers before and during the COVID-19 pandemic were evaluated

Results: Psychosocial screening levels remained stable during the pandemic. Psychosocial needs were identified for 36% of screeners prior to the COVID-19 pandemic and 33% during the COVID-19 pandemic. The need for IBH services increased during the COVID-19 time period resulting in a significant increase in IBH services

Conclusions: For CMC and their caregivers, psychosocial needs identified through psychosocial screening remained high during the pandemic, demonstrating the importance of screening for this population. The need for IBH services during the COVID-19 pandemic increased, underscoring the value and demand for these services particularly during an unprecedented time.

KEYWORDS

children with medical complexity, COVID-19 Pandemic, integrated behavioral health, psychosocial screening

1 | INTRODUCTION

Comprising nearly 20% of the U.S. population, children with special health care needs (CSHCN) are defined as children 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; Health Resources and Safety Administration Maternal and Child Health, 2020). Children with medical complexity (CMC), a subset of CSHCN, include children with complex medical needs characterized by chronic conditions, functional limitations, technology dependence, and high health care utilization

STATEMENT OF RELEVANCE TO THE FIELD OF INFANT AND EARLY CHILDHOOD MENTAL HEALTH

This study contributes to the field of infant and early childhood mental health by discussing the unique needs of young children with medical complexity and their caregivers a population at-risk for a myriad of psychosocial stressors that impact child and family wellbeing and health outcomes. Further, this study evaluates adaptations of integrated behavioral health screening and support services in the midst of a worldwide health crisis where young children and their families faced extraordinary challenges such as reduced access to early learning settings, funding cuts to key developmental services, decreased access to nurturing relational contexts (e.g., extended family members), and a pronounced increase in adult caregiver stress, mental health issues, and psychosocial pressures.

(Cohn et al., 2020). They are estimated to make up 3.2% of the population yet account for 40% of child Medicaid costs due to the level of medical support they require (Allshouse et al., 2018; Barnert et al., 2018).

The incidence of CMC has increased in recent years due to medical advances improving survival rates for infants born prematurely or with chronic conditions and coinciding advances in treating chronic illness (Perrin et al., 2014; Strickland et al., 2011). These advances mean that more children are requiring higher levels of medical care and experiencing subsequent developmental and behavioral health concerns (Strickland et al., 2011). Included in this population are infants with complex medical needs that require frequent medical visits during the first year of life to address medical needs correlated with prematurity (Kuo et al., 2017). The burden of navigating these complex care systems and medical needs largely falls on caregivers, highlighting the importance of understanding the impact of these unique stressors on child and family well-being and mental health.

1.1 | Psychosocial stressors for families of CMC

Caregivers of CMC often experience unique stressors including navigating complex and fragmented systems of medical care, providing and accessing supplemental

KEY FINDINGS AND THEIR IMPLICATIONS FOR PRACTICE/POLICY

1. Comparing psychosocial screening data pre-COVID-19 and during the COVID-19 pandemic highlighted that young CMC caregivers continued to experience a similar rate of positive psychosocial screeners. Psychosocial needs were identified in 36% of psychosocial screeners during the pre-COVID-19 pandemic and 33% during the COVID-19 pandemic time period. The results highlight this population's elevated level of stressors prior to the COVID-19 pandemic remained stable and are consistent with previous literature indicating that psychosocial stressors are higher for caregivers with CMC compared to caregivers of a child without medical complexity.
2. The level of integrated behavioral health (IBH) services increased during the COVID-19 pandemic. Specifically, there was a significant increase in IBH services completed with young children during the COVID-19 pandemic, underscoring the value and the demand for these services during this time. Further, it highlights that the psychosocial screener should be considered just one tool in an array of IBH services to help assess for psychosocial and behavioral health needs for CMC and their families. Additional assessment and discussion during the medical visit are essential in further identifying family needs that might go unaddressed otherwise.
3. All but one of the most common social determinants of health (SDOH) items on the psychosocial screener remained consistent and all of the most common psychosocial adversity screener items were consistent before and during the pandemic. Specifically, during the COVID-19 pandemic time period, caregivers identified worry related to their child's educational needs as the third most common SDOH item endorsed. Considering the disruption to children's school supports, the transition to online learning, and more limited access to special education services during the COVID-19 pandemic, it is not surprising that worry related to a child's educational needs was more common during the pandemic.

therapy, and finding appropriate educational settings for their children. These caregivers also frequently experience increased financial burden due to paying for medical supplies and equipment, inadequate insurance coverage, job or income loss because of time needed for appointments, social isolation and limited social support, and lack of adequate training for in-home child medical care (Allshouse et al., 2018; Psihogios et al., 2019). Further, CMC have more frequent inpatient admissions due to their complex needs, which result in an increase in psychosocial stressors related to disruption of family routines and caregiver's ability to work (Kuo & Turchi, 2021; O-Mahony et al., 2013). Consequently, caregivers of CMC experience increased levels of chronic stress when compared to other caregivers (Miodrag & Hodapp, 2010), with caregivers of CMC from communities of color experiencing disproportionately higher levels of stressors related to their child's medical care (e.g., increased amount of time managing medical care and care coordination, Mooney-Doyle & Lindley, 2020).

The impact on caregiver well-being is vast and may include chronic sleep concerns, reduced time with partner and other children, lack of time for self-care, diminished mental health, and lower levels of health-related quality of life (Cohn et al., 2020; Keilty et al., 2017; McCann et al., 2015; Meltzer, 2006; Yu et al., 2020). Caregiver stress can also affect completion of CMC medical cares, which has important implications for CMC (Psihogios et al., 2019). Specifically, due to their medical complexity, CMC often require intensive medical care in the home setting that is essential and life sustaining. Caregivers must often navigate multiple medication schedules, frequent medical equipment changes, and medical technology management requiring an awake and alert caregiver monitoring the child 24 h a day. The critical nature of this role highlights the urgency of addressing the stressors impacting the caregivers of CMC and their ability to complete their child's medical cares (Psihogios et al., 2019).

Data from the 2017 National Survey of Children's Health (U.S. Census Bureau, 2018) indicated that when compared to children without special health care needs, CMC and their caregivers were more likely to experience run-down housing and vandalism in their neighborhood, lower quality of caregiver physical and mental health, family income lower than 200% federal poverty level, parental divorce, parental incarceration, child abuse, and food insecurity (Berry et al., 2020). Thus, it is not surprising that a study of psychosocial stressors among caregivers of CMC found their scores on the Psychosocial Assessment Tool to be among the highest across published studies examining the measure in pediatric populations (Verma et al., 2020) and that psychosocial stressors are higher for care-

givers of CMC compared to caregivers of children without medical complexity (Buchholz et al., 2021). Chronic caregiver stress and unaddressed behavioral health needs also impact child well-being and development and is associated with lower levels of parenting responsiveness, higher levels of child behavior concerns, and lower child language scores (Dempsey & Keller-Margulis, 2020; Neece, 2014; Smith, 2004; Woodward et al., 2011).

The psychosocial stressors are further compounded for CMC involved with the child protection services system. CMC are overrepresented in the child protective services system with 30% of children in foster care having at least one chronic condition (Seltzer et al., 2017) and 10% of children in foster care identified as having more complex medical needs (American Academy of Pediatrics, 2021). Once in the foster care system CMC are at increased risk for neglect, have a higher likelihood of placement in a group home or institution, and are more likely to experience placement instability (Seltzer et al., 2017). The significant impact of psychosocial stressors, and social determinants of health (SDOH) broadly, on child and family health and well-being, highlights the need to assess and address SDOH including economic stability, education access and quality, social and community context, health and health care access and quality, and neighborhood environment (Center for Disease Control and Prevention, n.d.) and child and caregiver behavioral health needs for CMC and their families.

Barnert et al. (2018), evaluated health outcomes to identify those most critical to the health and well-being of CMC. The ten health outcomes identified included: "having basic needs met, inclusive education, child social integration, current child health-related quality of life, long-term child self-sufficiency, family social integration, community system supports, health care system supports, high quality patient-centered medical home, and family-centered care. (Barnert et al., 2018)." As indicated by Barnert et al. (2018), a large number of health-related outcomes for CMC were directly related to SDOH and child and family well-being, further underscoring the importance of assessing and providing psychosocial and behavioral health supports for CMC and their families (Barnert et al., 2018; Cohn et al., 2020).

1.2 | Psychosocial stress during the COVID-19 pandemic

Before the COVID-19 pandemic, families of CMC encountered difficulty accessing care for their child, navigated fragmented systems of care, and spent more time on the tasks of caring for their child than caregivers without CMC

(Allshouse et al., 2018; Hexem et al., 2011). The onset of the global pandemic uniquely affected CMC and their families due to the presence of medical complexity in the family. Initial reporting on the effect of COVID-19 pandemic on children stated that children tended to exhibit mild or no symptoms if infected. However, initial reporting also indicated that for adults, those with chronic health conditions appeared to exhibit more severe symptoms and have worse health outcomes, including death. Understandably, families of CMC were concerned that their more medically complex and medically fragile child would have poor health outcomes if infected with COVID-19. This strong worry, coupled with the COVID-19 pandemic-related shutdown of services, led to disruption in services and psychosocial supports for CMC and their families. Consequently, caregivers were placed in the untenable position of fulfilling the many roles impacted by service disruptions (e.g., physical therapist, speech therapist, special education teacher) while having even more limited home health support and delays in accessing medical care and receiving necessary equipment, further exacerbating caregiver psychosocial stress. Coinciding with the COVID-19 pandemic were multiple instances of racial injustice, disparity, and civil unrest, particularly in the United States, directly impacting the health and well-being of communities of color and leading to increased awareness of the systemic racism rooted within systems of care.

1.3 | Integrated behavioral health services for CMC

Primary care settings monitor both physical and mental health and provide prevention and early identification services to children in the context of well-child care (Centers for Medicare and Medicaid Services, n.d.). Primary care is a universal essential service designed to promote health and prevent systemic inequities from taking root. Integrated behavioral health (IBH) services enable primary care clinics to provide high-quality, comprehensive care to children and their families. When IBH clinicians with expertise in child development, infant, and perinatal mental health are embedded in a primary care clinic, young children and their families receive access to resources that may be otherwise inaccessible (Buchholz et al., 2018; Talmi et al., 2020). Behavioral health needs often present in primary care settings first due to the trusting relationships families frequently have with their child's medical provider. IBH clinicians embedded into the primary care setting can increase accessibility for behavioral health services. Further, IBH services in primary care are associated with

improved behavioral health outcomes relative to usual care (Asarnow et al., 2015).

Primary care is particularly important for young CMC and their caregivers, serving as an opportune place for caregivers to receive support as they develop and adapt their parenting style to their child over time. Primary care clinics help caregivers engage in care coordination with other specialties or community agencies and provide ongoing surveillance and standardized screening for CMC physical, developmental, cognitive, behavioral, and emotional needs, in addition to caregiver and family needs (e.g., SDOH). Furthermore, due to young CMC risk for developmental delays and their caregivers' risk of impaired well-being, the primary care setting provides an opportunity for ongoing discussion and monitoring of symptoms while also affording a variety of behavioral health supports and interventions that are individualized to CMC and their family's needs overtime (Bradshaw et al., 2019).

During the COVID-19 pandemic, young children and their families faced unthinkable challenges such as reduced access to early learning settings, funding cuts to key developmental services, a shortage of private duty nursing and home health care, decreased access to nurturing relational contexts (e.g., extended family members), and a pronounced increase in adult caregiver stress, mental health issues, and psychosocial pressures. Early childhood IBH clinicians in primary care settings support families in navigating these enormous challenges and promote whole-child and whole-family health. Due to the COVID-19 pandemic-related shutdown of many services, primary care providers were among the few professionals with whom families of CMC were interacting. Thus, universal psychosocial screening and other IBH supportive services in the primary care setting offered a valuable opportunity to connect with families in the midst of a significant worldwide health crisis to help identify and address psychosocial concerns impacting child and family well-being among CMC and their families.

1.4 | Purpose of the study

The purpose of this study is to characterize screening for SDOH and psychosocial adversity and providing IBH support during the medical visit at a primary care clinic for CMC before and during the COVID-19 pandemic. Aims are to (1) compare levels of psychosocial stressors prior to and during the COVID-19 pandemic for CMC and their families, and (2) describe adaptations to psychosocial screening procedures and IBH supports for CMC before and during the COVID-19 pandemic.

2 | METHODS

2.1 | Setting

The study was conducted in a primary care clinic for CMC located in a children's hospital in the mountain west and was approved by the hospital's Institutional Review Board. The primary care clinic serves over 4500 CMC, of whom 1300 children are under 5 years old. Nearly 2000 of the patients in this clinic are co-managed, meaning that they receive their primary care from a medical provider outside of the clinic and are provided specialty care for their medical complexity at the clinic. Both CMC and their caregivers who received their primary medical care outside of the clinic and those who received their primary care within the clinic were included in the study. This clinic also serves as the hospital's neonatal intensive care unit (NICU) graduate clinic. Eligibility criteria to become a patient in the clinic are (a) suspected or confirmed genetic diagnoses, (b) receive care from at least two medical specialties, or (c) be a sibling of a child who meets criterion (a) or (b). Children in the latter category are generally medically healthy or have mild medical concerns that could be served in a typical primary care setting; however, to provide family-centered care, they are accepted as patients in the clinic.

Care in the clinic is provided by an interdisciplinary team of primary care medical providers (physicians and nurse practitioners), nurses, pharmacists, dietitians, and several medical specialists (e.g., gynecologist, geneticist). An IBH team is fully integrated into the clinic and includes psychologists, a psychiatrist, and psychology and psychiatry trainees. Additional clinic staff include a social worker, nurse care coordinators, and health navigators, who assist families with community and educational system navigation.

2.2 | Psychosocial screening

An internally developed and institutionally adopted, 14-question psychosocial screener is used within the clinic to screen for SDOH including food insecurity, insurance or public benefits access, health care and educational system navigation; in addition to psychosocial adversity including caregiver behavioral health or substance use, or exposure to intimate partner violence (Buchholz, et al., 2021; Talmi & Poole, 2010). For this specific screener, items 1–9 focus on SDOH and 10–14 focus on psychosocial adversity. The goal of screening is to identify and discuss SDOH and psychosocial needs with the family and to respond to needs identified by connecting the family with additional clinic support and community resources, as desired. The psychosocial screener is available in eleven languages and

is administered at the first visit in the clinic and every 6 months thereafter. A paper copy of the psychosocial screener is given to the caregiver in their primary language by a medical assistant at the beginning of the medical visit. The screener is included in Figure 1.

2.3 | Review and response to screener results

The patient's medical provider reviews the results of the psychosocial screener with the family, discussing endorsed items and assessing overall psychosocial stressors and behavioral health concerns. The medical provider consults with the appropriate team member to address concerns based on the nature of the item endorsed (e.g., health navigator, social work, IBH team) and/or concerns identified through conversation during the medical visit. The health navigator supports families with concerns related to the following SDOH: food resources, medical transportation, educational issues, public benefits access, housing, and guardianship. The social worker addresses concerns related to the following psychosocial adversity situations: caregiver behavioral health, substance use concerns among those living in the home, and intimate partner violence. The IBH team member provides support for concerns about the child-caregiver relationship, child and family well-being, and/or developmental, behavioral, emotional concerns. The IBH team also provides support related to caregiver behavioral health. The health navigator, social worker, and IBH team, are all fully integrated into the clinic and meet with the family as part of their regular care in clinic.

IBH services include consultation with families and primary care team members and short-term behavioral health (STBH) therapy, and services are provided for families with or without an elevated psychosocial screener. When meeting with CMC and their caregivers to provide services (e.g., initial consult, follow up consult, STBH therapy), the IBH team assesses CMC and their caregiver's needs and provides recommendations to support the family. Following the visit, the IBH team discusses recommendations with the CMC's medical provider and other relevant team members (e.g., social worker).

2.4 | Adaptations during COVID-19 pandemic

In March 2020, clinic processes were significantly impacted by the COVID-19 pandemic. Because it is a primary care clinic that provides vital well-child care for young children and sick visits for non-COVID issues, the

The questions below ask about things you may have been through that can affect your family and your child's health. We are here to help and we can give you information and resources to help you get the care your family needs. Your answers are important to us and will be kept private as part of your child's medical record.

1. Do you need help finding a doctor or clinic for yourself?	YES	NO
2. Do you have any concerns or problems that make it hard for you to keep your child's health appointments or manage your child's health care? Please circle all that apply: job, transportation, childcare, insurance, money, relationship difficulties, work or school stress, chronic illness, or legal problems	YES	NO
3. In the last 3 months, did you ever feel stressed about making ends meet? Please circle all that apply: rent/mortgage, formula, diapers, childcare, gas/transportation, paying bills, other _____	YES	NO
4. In the last 3 months, did you ever worry that your food would run out before you had money to buy more?	YES	NO
5. In the last 3 months, did your food ever not last and you didn't have money to get more?	YES	NO
6. Are you worried about your benefits right now? For example, have your benefits been denied, reduced, or eliminated or do you need help renewing your benefits? Please circle all that apply: Medicaid/CHP Food Stamps (SNAP) Temporary Assistance for Needy Families (TANF) WIC Child Care Assistance Program (CCAP) Unemployment Insurance Social Security Disability (SSI/SSDI) Other: _____	YES	NO
7. Do you have concerns about your child's education needs? (IEP, 504 plan, suspensions)	YES	NO
8. Do have concerns about your housing or becoming homeless?	YES	NO
9. Do you need help with the following? Please circle all that apply: Guardianship of a Minor Child Guardianship of a Disabled Adult	YES	NO
10. Do you want to talk to someone about feeling alone or needing someone to rely on when you have problems?	YES	NO
11. Do you or anyone else in your home have a problem with alcohol or marijuana?	YES	NO
12. Do you or anyone else in your home use medicine not prescribed to you, or any other type of drugs (such as cocaine, heroin, or meth)?	YES	NO
13. Have you or your child recently been threatened, hit, or touched in an unwanted way?	YES	NO
14. a. Do you feel sad, hopeless, or anxious a lot of the time?	YES	NO
b. If yes, have you had recent thoughts of harming yourself or others?	YES	NO

FIGURE 1 Psychosocial screener used in the primary care clinic

clinic never completely closed to patients. However, the clinic moved to a hybrid telehealth and in-person model in March 2020, and a lower percentage of patients attended in-person clinic visits to reduce the spread of COVID-19. In-person well-child visits were restricted to children 3 years of age and under and patients whose in-person visits were deemed medically necessary by the provider. In-person sick visits were restricted to those who were not COVID-19 positive or who did not have known COVID-19 exposure.

As clinic services transitioned to a hybrid model, the IBH team made several adaptations to the model of care described above. The transition to telehealth services required creating clinical guidelines and practice considerations for telehealth, clinic processes for multiple members providing services via telehealth, and telehealth safety and risk procedures related to behavioral health concerns regarding risk (e.g., suicidal ideation, concern for intimate partner violence). The most significant service provisional adaptation to IBH was transitioning nearly all behavioral health services to telehealth modalities. Patients who were present in clinic, but who either were not appropriate to see in-person due to possible COVID-19 symptoms or who preferred not to see the IBH team member in-person, were seen via an electronic tablet that was brought into the exam room. For patients in telehealth visits, IBH services were provided via telehealth. Notably, the opportunities for case discussion or a warm handoff between team members, which is a key aspect of integrated care, were fewer during the clinic visits with the hybrid model than the non-hybrid model used prior to the COVID-19 pandemic.

Additional adaptations were made to health promotion/prevention and intervention services. Specifically, the IBH team reviewed the charts of patients who previously received IBH services to identify those who would benefit from phone follow-up to assess child and family well-being and identify any needs for additional behavioral health and psychosocial support. The IBH team also created caregiver information and resource content related to child and family well-being during the COVID-19 pandemic that were distributed across team members and could be provided to families electronically or in paper form by any team member as needed. Furthermore, resources for families and the clinic team related to the topics of diversity, equity, and inclusion were distributed to provide support during the instances of racial injustice, disparity, and civil unrest occurring during the COVID-19 pandemic. Finally, the IBH team began to offer telehealth STBH services to address new concerns resulting from the COVID-19 pandemic.

2.5 | Analysis

The term *pre-COVID-19 time period* describes the data evaluated prior to the COVID-19 pandemic, specifically between March 2019 and December 2019. The term *COVID-19 time period* describes the data evaluated during the COVID-19 pandemic, specifically between March 2020 and December 2020. This terminology is used throughout to discuss the results of the study. Statistical analyses were completed to evaluate characteristics between the two groups included in the pre-COVID-19 time period and COVID-19 time period using independent t-test and chi-square tests as appropriate. Subsequently, multiple logistic regression was used to estimate the adjusted odds ratios and 95% confidence intervals of the frequency of positive psychosocial screeners and frequency of IBH services completed across visits in the primary care clinic, comparing the pre-COVID-19 time period and COVID-19 time period across the following variables: number of visits with a positive psychosocial screener, positive SDOH item on the psychosocial screener, positive psychosocial adversity item on the psychosocial screener, positive psychosocial screener and IBH services, and IBH services for young CMC and their families. Additionally, all models were adjusted for the following covariates: race and ethnicity. Significance level was specified at $P < .05$.

3 | RESULTS

3.1 | Screening totals and rates

This study included demographic data for young CMC, defined as children 5 years and younger, and psychosocial screening and IBH service data across all visits completed with young CMC and their caregivers. Demographic data for young CMC children included in the study are presented in Table 1. The majority of young CMC children in the study identified their race as White (55% pre-COVID-19 time period, 51% COVID-19 time period) and their ethnicity as Not Hispanic/Latino (60% pre-COVID-19 time period, 57% COVID-19 time period). English was identified as the primary language for the majority of children (83% pre-COVID-19 time period, 86% COVID-19 time period) and most had public insurance (73% pre-COVID-19 time, 72% COVID-19 time period). There were significant differences for both race and ethnicity between young CMC children included in the pre-COVID-19 time period compared to the COVID-19 time period; therefore, all models were adjusted for the following covariates: race and ethnicity.

TABLE 1 Patient demographics of young children (5-years-old and younger) pre-COVID-19 pandemic and during COVID-19 pandemic

	Pre-COVID-19 (March to December, 2019) (N = 1171)	During COVID-19 (March to December, 2020) (N = 1141)	P value*
Age in years, mean (SD)	2.7 (1.74)	2.7 (1.78)	.65
Sex			
Female	547 (47%)	558 (49%)	.29
Male	624 (53%)	583 (51%)	
Race	Total	Total	
American Indian	7 (.6%)	11 (1%)	<.001*
Asian	29 (2%)	23 (2%)	
Black	102 (9%)	86 (7%)	
Multiple	146 (13%)	154 (14%)	
Native Hawaiian or Other Pacific Islander	7 (.6%)	11 (1%)	
Other	166 (14%)	147 (13%)	
Unknown	75 (6%)	139 (12%)	
White	646 (55%)	581 (51%)	
Ethnicity			
Hispanic/Latino	375 (32%)	334 (29%)	<.001*
Not Hispanic/Latino	703 (60%)	652 (57%)	
Unknown	93 (8%)	155 (14%)	
Language			
English	973 (83%)	981 (86%)	.13
Other	139 (12%)	117 (10%)	
Spanish	59 (5%)	43 (4%)	
Insurance			
Public	855 (73%)	818 (72%)	.67
Private	281 (24%)	291 (25%)	
Mix of Private and Public	31 (2.6%)	28 (2.5%)	
Other/Unknown	4 (.4%)	4 (.4%)	

Note. Statistical significance was determined using independent t-test or Pearson's Chi-square test as appropriate between pre COVID-19 and during COVID-19 time period.

* $P < .05$.

TABLE 2 Psychosocial screening results for families of young children pre-COVID-19 pandemic and during COVID-19 pandemic

	Pre-COVID-19 pandemic (March to December, 2019)	During COVID-19 pandemic (March to December, 2020)	Adjusted OR (95% CI)	Wald Chi-Sq (DF), P value
Total completed	660	600		
Total positive (at least one item 1–14)	235 (36%)	198 (33%)	0.85 (0.67, 1.09)	1.62 (1), 0.20
Total positive SDOH (at least one item 1–9)	229 (35%)	195 (33%)	0.87 (0.68, 1.11)	1.29 (1), 0.26
Total positive psychosocial adversity (at least one item 10–14)	53 (8%)	46 (8%)	0.74 (0.47, 1.15)	1.80 (1), 0.18
Positive screener and met with IBH	74 (31%)	88 (44%)	1.56 (1.06, 2.41)	4.99 (1), 0.03*

* $p < 0.05$.

Psychosocial screening data across all visits completed in the primary care clinic during the pre-COVID-19 and COVID-19 time periods are included in Table 2. During the pre-COVID-19 time period, 660 psychosocial screen-

ers were completed by caregivers of young CMC. Of the 660 screeners completed, there were a total of 235 (36%) positive psychosocial screeners, with 229 (35%) positive for SDOH (i.e., items 1–9) and 53 (8%) positive for

psychosocial adversity (i.e., items 10–14). During the COVID-19 time period, 600 psychosocial screeners were completed by caregivers of young CMC. Of the 600 screeners completed, there were a total of 198 (33%) positive psychosocial screeners, with 195 (33%) positive for SDOH and 46 (8%) positive for psychosocial adversity. The number of positive psychosocial screeners between the pre-COVID-19 and COVID-19 time periods were evaluated and are included in Table 2. There was not a significant difference between the number of positive screeners during the pre-COVID-19 time period and the COVID-19 time period. Notably, rates of screening for young children did not decrease as drastically as the rates for older children during the COVID-19 time period because young children continued to receive care in-person at the clinic.

Regarding behavioral health interventions and responses to positive psychosocial screeners, during the pre-COVID-19 time period, 31% of families with a positive psychosocial screener met with the IBH team. During the COVID-19 time period, 44% of families with a positive psychosocial screener met with the IBH team. While the clinic's health navigators are assigned for follow-up to items 1–9 and the IBH team or social worker respond to items 10–14, the IBH team can be consulted regardless of whether there is an endorsed item on the psychosocial screener. Therefore, information gathered independently of the psychosocial screener (e.g., caregiver report, provider concerns, postpartum depression screener) may have contributed to the number of IBH services for families with a positive screener. There was a statistically significant increase in the number of IBH services for families with a positive screener during the COVID-19 time period as compared with the pre COVID-19 period (see Table 2).

3.2 | Most common SDOH and psychosocial adversity items

Table 3 include data and analysis for the most common SDOH and psychosocial adversity items. During the pre-COVID-19 time period, the most common SDOH items endorsed of the nine items listed on the psychosocial screener were as follows: (1) financial stress (26%; e.g., paying bills, childcare, gas/transportation); (2) benefits (21%; e.g., Medicaid, social security disability); (3) difficulty managing child's healthcare (11%); and (4) food insecurity (10%). During the pre-COVID-19 time period, the most common psychosocial adversity items endorsed were: (1) caregiver mood symptoms (56%), and (2) social isolation (26%). During the COVID-19 time period, the most common SDOH were as follows: (1) financial stress (25%); (2) benefits (17%); (3) child education needs (13%); and (4)

food insecurity (11%). During the COVID-19 time period, the most common psychosocial adversity items endorsed were consistent with pre-COVID-19 time period data, with caregiver mood symptoms (58%) and social isolation (37%). Notably, worry about child education needs was a more common SDOH during the COVID-19 time period when access to educational services was substantially impacted and CMC were transitioning to remote learning.

3.3 | IBH team services pre- and during the COVID-19 pandemic

Table 4 provide the data and analysis of IBH services provided during the pre-COVID-19 time period and during the COVID-19 time period across all visits completed in the primary care clinic. This data included when a young CMC and their family were seen by the IBH team for multiple visits. During the pre-COVID-19 time period, there were a total of 3834 well-child, follow-up, and same day sick visits completed with young CMC (i.e., children under 5-years-old) and their families in the primary care clinic, representing 44% of total clinic visits of all patients seen during this time period. The IBH team met with families during 502 (13%) of these visits. Of the visits with families who received IBH services during the pre-COVID-19 time period, 85% did not have a positive psychosocial screener. During the COVID-19 time period, there were a total of 3454 visits completed with young CMC and their families in the clinic (44% of the total clinic visits) and the IBH team met with families during 872 (25%) of these visits. Of the visits with families who received IBH services during the COVID-19 time period, 90% did not have a positive psychosocial screener. All IBH services were included in the data collected, therefore services included single consults, follow-up consults, and STBH sessions with the IBH team. Additional analysis of the pre-COVID-19 time period and the COVID-19 time period are included in Table 4. There was a statistically significant increase in the number of IBH services completed during the COVID-19 time period, compared to the pre-COVID-19 time period.

3.4 | IBH team most common recommendations

Table 5 include the data and analysis completed for the most common recommendations provided by the IBH team. Following an elevated screener or when a child or caregiver behavioral health need is identified during a medical visit via other means, clinic protocol is for the IBH team to meet with the young CMC and their caregiver. During the pre-COVID-19 time period, the four

TABLE 3 Most common positive psychosocial screening items for families of young children pre-COVID-19 pandemic and during COVID-19 pandemic

	Pre-COVID-19 pandemic	During COVID-19 pandemic	Chi Sq (DF), P value
Total SDOH positive items	492	421	
Most common positive SDOH (items 1–8)			
1. Financial stress	130 (26%)	105 (25%)	0.26 (1), 0.61
2. Worry about benefits	104 (21%)	70 (17%)	2.99 (1), 0.08
3.			
• Difficulties managing child's healthcare (<i>pre-COVID-19 Pandemic</i>)	56 (11%)	42 (10%)	0.47 (1), 0.49
• Child education needs (<i>during COVID-19 Pandemic</i>)	43 (9%)	55 (13%)	4.43 (1), 0.04*
4. Food insecurity	49 (10%)	48 (11%)	0.50 (1), 0.48
Total psychosocial adversity positive items	54	38	
Most common psychosocial adversity (Items 10–14)			
1. Caregiver mood symptoms	30 (56%)	22 (58%)	0.05 (1), 0.82
2. Social isolation	14 (26%)	14 (37%)	1.26 (1), 0.26

*p < 0.05.

TABLE 4 Number of primary care clinic visits and IBH services for families of young children pre-COVID-19 and during COVID-19 pandemic

	Pre-COVID-19 (March to December, 2019)	During COVID-19 (March to December, 2020)	Adjusted OR (95% CI) by visit	Chi-Sq (DF), P value
Total number of primary care clinic visits for children ≤5 years	3834	3454		
Total number of IBH services for children ≤5 years	502 (13%)	872 (25%)	2.19 (1.94, 2.47)	159.0 (1), < 0.001
Total number of IBH services and a positive psychosocial screener	428 (85%)	784 (90%)		

TABLE 5 Most common IBH recommendations for families of young children pre-COVID-19 pandemic and during COVID-19 pandemic

	Pre-COVID-19 pandemic	During COVID-19 pandemic	Chi Sq (DF), P value
Total IBH recommendations provided	1233	2039	
Most common IBH recommendations			
1. IBH follow up	369 (30%)	748 (37%)	15.61 (1), < 0.001*
2. Developmental and behavioral strategies discussed	320 (26%)	505 (25%)	0.57 (1), 0.45
3. Developmental and behavioral resources provided	199 (16%)	319 (16%)	0.14 (1), 0.71
4. Refer family member to community mental health services	112 (9%)	105 (5%)	19.20 (1), < 0.001*

*P < .05.

most common IBH recommendations provided to families across IBH visit types were: (1) follow up with IBH team (30%); (2) developmental and/or behavioral strategies discussed (26%); (3) developmental and/or behavioral resources provided (16%); and (4) referral of family member to community mental health services (9%). During the COVID-19 time period the most common IBH team recommendations remained consistent with the results of

the pre-COVID-19 time period. However, the frequency with which they were recommended differed: follow up with the IBH team (37%) developmental and/or behavioral resources discussed (25%), and referral of family member to community mental health services (5%). Notably, IBH follow up was more frequently recommended during the COVID-10 time period compared to the pre-COVID-19 time period, while referral of a family member to

community mental health services was recommended less during the COVID-19 time period compared to the pre-COVID-19 time period. This is likely due to the disruption in services during the COVID-19 pandemic resulting in an increase need for IBH services to account for decreased community services available during the COVID-19 pandemic.

4 | DISCUSSION

Psychosocial adversity at the child, family, and community levels directly impacts the health and well-being of pediatric populations, and SDOH are highly predictive of health outcomes for both adults and children (Felitti et al., 1998; Garg et al., 2015; Garner et al., 2012). Understanding family circumstances and environmental contexts includes examining how psychosocial complexity and behavioral health needs impact health and well-being for all members of the family. However, in primary care and community settings, it is often challenging to address family or caregiver stressors and health disparities because the healthcare system identifies the child as the patient, not the caregivers or family unit. Screening families for psychosocial stressors is not only within the scope of pediatric primary care settings, but imperative to do in one of the few settings children and families could access during the COVID-19 pandemic. It is critically important for primary care providers to identify and address these concerns as early as possible in the context of well-child care. The COVID-19 pandemic exacerbated existing health disparities; therefore, it has been especially important during this time to ask families about their needs, identify risk factors related to SDOH and psychosocial adversity, and to be prepared to support families with the resources they need to address these challenges.

Prior to the COVID-19 pandemic, CMC and their caregivers experienced an increased risk for multiple psychosocial stressors that can impact child and family well-being and health outcomes. During the COVID-19 pandemic, when access to supports diminished, psychosocial screening and behavioral health support in the primary care setting was crucial in identifying and addressing the unique circumstances and needs of CMC and their families.

Results of the current study indicate that the increased risk of SDOH and psychosocial adversity for CMC and their families persisted through at least the first 10 months of the COVID-19 pandemic. The results highlight this population's increased level of stressors prior to the COVID-19 pandemic and is consistent with previous literature indicating that psychosocial stressors are higher for caregivers with CMC compared to caregivers of a child without medical complexity (Buchholz et al., 2021). Additionally, all but

one of the most common SDOH items remained consistent and all of the most common psychosocial adversity factors were consistent before and during the COVID-19 pandemic. Specifically, during the COVID-19 pandemic time period, caregivers identified worry related to their child's educational needs as the third most frequent SDOH item endorsed. Considering the disruption to children's school supports, the transition to online learning, and more limited access to special education services during the COVID-19 pandemic, it is not surprising that worry related to child's educational needs was more common during the pandemic.

Further, the findings of this study demonstrate that while overall psychosocial screening levels remained stable, the need for IBH services increased during the COVID-19 pandemic. Specifically, there was a significant increase in IBH services completed with young children during the COVID-19 time period compared to the pre-COVID-19 time period, underscoring the value and the demand for these services, particularly during an unprecedented time.

The increased need for IBH services, even in the absence of a positive psychosocial screener, as described in Table 4, has some implications for CMC and their caregivers. First, during the COVID-19 pandemic, IBH support was utilized more often, in part because of service disruptions in other critical domains and unique stressors experienced by CMC families. Second, it highlights that the psychosocial screener should be considered just one tool to identify psychosocial and behavioral health needs for CMC and their families. Especially since the psychosocial screener is only administered every 6 months in the clinic. Additional assessment and discussion during the medical visit are essential in identifying family needs that might go unaddressed otherwise.

4.1 | Utilizing psychosocial screening during COVID-19 pandemic

During the COVID-19 pandemic some screening and follow-up processes remained consistent while others changed. Since young CMC continued to receive their well-child care in-person, these types of visits were not impacted and the psychosocial screener could be completed in the paper format. Completion of the screener was important in monitoring changes in SDOH and psychosocial adversity as the COVID-19 pandemic continued and impacted the economy, communities, and systems of care (e.g., health care, education, early developmental services). Additionally, as a result of unemployment or health care costs due to the COVID-19 pandemic, some families experienced a high level of financial strain. A benefit of universal screening is that all families are screened for SDOH and

psychosocial adversity, regardless of previous psychosocial circumstances, and caregivers can communicate new and existing areas of psychosocial need with their primary care team. However, the number of in-person visits was reduced during the COVID-19 pandemic for these patients and universal screening was not administered electronically for telehealth visits. To account for fewer psychosocial screening opportunities and the general presence of a significant worldwide health crisis, proactive measures (i.e., chart review and phone calls) were used to identify families with risk for high psychosocial stress. Additionally, adjustments were made to the questions asked during telehealth visits to assess for psychosocial stressors and adversity, and resources were provided for all families (e.g., COVID-19 resources that could be distributed by any team member).

Procedural changes were made at both the medical system level and at the IBH team level to provide quality telehealth services to patients and families. This included developing new workflows and systems to screen for psychosocial stressors, respond to screeners and psychosocial and behavioral health needs, and update clinical procedures for assessing and responding to risk and safety concerns identified during telehealth visits. Additionally, in an effort to lower the amount of in-person contact, the IBH team transitioned their current systems to be able to provide services via electronic tablet, if needed, during in clinic visits. Given that telehealth will likely continue as a common service modality after the COVID-19 pandemic subsides, it is important to identify processes to allow for psychosocial screening via telehealth visits. If electronic medical records are used, the screener may be sent electronically. At a minimum, the provider can ask open-ended questions to assess psychosocial well-being (e.g., "How has it been caring for your child during the pandemic? Has anything made it difficult or challenging to provide for your child?").

4.2 | Supporting CMC and their caregivers during the COVID-19 pandemic

Though a high-level of psychosocial stress is not new for many families of CMC, the unique stress and changes as a result of a global pandemic are new. When working with families of CMC during the initial months of the COVID-19 pandemic, a common theme that emerged was that social isolation, strict hand hygiene, precautions around individuals with illness symptoms, and worry about health of their child or family were not entirely new to the caregivers. Some caregivers even noted that it felt validating that the restrictions that characterized the life of their child and family during annual respiratory season or year around,

were found to be stressful by families without CMC. However, caregivers also noted that the support networks that they relied on prior to the pandemic were now less available for support.

Further, COVID-19 pandemic-related shutdowns and public health guidance for social distancing, in combination with concern over a CMC becoming infected with COVID-19, led to an unprecedented level of social isolation and disconnection from care and support networks. Caregivers of CMC shared a number of themes related to COVID-19 pandemic-induced stressors including, loss of therapeutic, medical, and educational services and supports; an increase in caregivers' roles and responsibilities; changes in medical care resulting in increasingly fragmented care; less access to medical and behavioral health care due to being a higher-risk population for contracting COVID-19; and the overall impact of these stressors on child and family well-being.

During the COVID-19 pandemic, many therapeutic, educational, and developmental services for young children were initially stopped and were then predominately provided via telehealth. The substantial and rapid change in the level and modality of support and the ongoing limited access to in-person support increased the burden on caregivers. Furthermore, they were tasked with managing the increase in their child's behaviors and emotional concerns as a result of their child's loss of therapeutic support, wellness activities, and change in schedule and structure. Families frequently shared with the IBH team that they were completing excessive hours of telehealth appointments (e.g., 8–10 h a day) for their CMC, sharing how difficult it was to balance on-line schooling, Early Intervention therapies, medical appointments, and additional therapies with a young child, where telehealth modalities are less than ideal. Furthermore, caregivers reported that their child was disengaged in telehealth and they were, therefore, burdened with the task of having to manage talking to therapists and medical providers via telehealth while attempting to manage their child's behaviors and lack of interest in this therapy modality.

Additionally, the COVID-19 pandemic resulted in cancellation and delay for routine surgeries (e.g., cleft palate repair) and specialty visits that impacted the ability for CMC to receive the breadth of medical support needed to manage their complex needs. This shift resulted in increasingly fragmented care and the prolonging of medically recommended surgeries that were deemed non-urgent during the COVID-19 pandemic. For a number of CMC, in-home nursing was cancelled or delayed, further increasing the burden on caregivers to complete all of their child's medical care. This is particularly important to consider for CMC with tracheostomies given that they require being attended to by a trained caregiver 24 h a day.

4.3 | Behavioral health adaptations used during the COVID-19 pandemic

In addition to the IBH service adaptations previously discussed (e.g., telehealth option), the COVID-19 pandemic also required adaptations to the content of behavioral health service provision, such as the questions asked, the intervention strategies used, and the resources provided. For example, IBH team members specifically asked families about their thoughts, reactions, and needs in relation to the COVID-19 pandemic. Additionally, the race-related social justice events of 2020 were occurring in conjunction with the COVID-19 pandemic. These events were also specifically discussed with families given the impact of social injustice on the lives of families and the racial differences in the rate of infection and death due to COVID-19 (Center for Disease Control & Prevention, 2021). Regarding intervention strategies, IBH consultation often included reflection with families about how they coped with social isolation during past respiratory seasons or during periods of illness for their CMC to help identify coping strategies for COVID-19 pandemic-related social isolation. When a pre-COVID-19 pandemic referral option was no longer applicable (e.g., parent support group), the IBH team member collaborated with the caregiver to discuss intrinsic resources to maximize as a buffer to psychosocial stressors. Additionally, as certain COVID-19 pandemic-related restrictions were lifted, families asked whether some in-person activities were safe (e.g., in-home or in-clinic developmental therapies, visiting with other families of CMC, in-person behavioral health services). The IBH team collaborated with the family, medical providers, and other relevant persons to identify the option that maximized safety with other dimensions of child and family well-being. These discussions helped families make responsible and informed choices about interactions with others for the sake of their child's development, behavioral health, physical health, and their family well-being.

The IBH team collaborated closely with families to develop creative strategies to meet their unique needs during the COVID-19 pandemic. Written resources were distributed in print and electronic format on topics such as supporting young children, caregiver well-being, CMC during the COVID-19 pandemic, and race and racial disparities, inequities, and injustice. Medical providers and support staff also had electronic access to these resources and were able to easily share them with CMC caregivers. Clinical and reflective practices were used to help create a more inclusive and equitable space for families to discuss disparities experienced within the healthcare system and other systems of care. The IBH team also utilized STBH sessions to accommodate the behavioral health needs of

CMC and their families during the COVID-19 pandemic when other support systems were unavailable.

4.4 | Limitations

The current study highlights the importance of screening and addressing SDOH and psychosocial adversity for CMC and their families in the context of primary care both before and during the COVID-19 pandemic. The psychosocial screener utilized in the current study was only available for patients seen in-person due to the unavailability of the screener in an electronic format. Due to this limitation, a lower number of screeners were distributed during the COVID-19 pandemic. Although the number was only slightly decreased due to patients under 3-years-old continuing to receive their well-child care in-person, future studies should consider exploring processes for completing all screeners electronically. This is especially important considering how the COVID-19 pandemic has changed the way healthcare service will be administered in the future and the likelihood of ongoing telehealth services.

Further, given that the study aims were to compare frequency of psychosocial needs and IBH services during the pre-COVID-19 and COVID-19 time periods, data were analyzed at the visit-level rather than patient-level to more fully capture the extent of psychosocial and IBH service needs. Structuring the data in this manner increased correlated data within each time period because some patients completed a psychosocial screener or received IBH services more than once in a time period. However, the psychosocial screener is administered every 6 months, thus across the 10 month period of March–December, a family could complete the measure a maximum of two times. Regarding IBH services, visit-level data allowed for examination of the extent of behavioral health needs rather than how many unique patients required IBH services; the latter is the interpretation permitted by patient-level data.

Lastly, although racism is a known SDOH that impacts health outcomes and child and family well-being (Trent et al., 2019), the psychosocial screener included in this study did not include an item that explicitly screened for racism. Racial and ethnic implicit biases impact health outcomes and patient and family experience within the healthcare system (FitzGerald & Hurst, 2017). Given the reality that a CMC requires more intensive medical care and has more frequent interactions with medical healthcare systems, there is an increased likelihood that families of color would experience the burden of systemic racism and racial biases within the medical system. Future studies should consider directly screening for racism within their psychosocial screening process and training providers and clinic staff in how to respond in a diversity-informed

manner to a caregiver report of experienced racism. Including an item related to racism can help to further identify and address racism as a known SDOH, and further assess its impact on young children and their caregivers.

4.5 | Future steps

Prior to the COVID-19 pandemic, CMC and their caregivers experienced a high level of stress that had important implications on child and family well-being (Cohn et al., 2020; Cousino & Hazen, 2013). Health outcomes for CMC are directly related to SDOH, underscoring the need for continued identification of and specific support for SDOH for CMC and their families (Barnert et al., 2018). During the COVID-19 pandemic, CMC and their caregivers continued to experience increased psychosocial stressors and there was an increase in IBH services in the clinic, demonstrating a clear need for IBH services within the primary care setting, especially when there is medical complexity. The psychosocial screener used in the current study was not designed specifically for CMC, thus there may be SDOH or psychosocial adversity domains that are not included on the screener but are relevant to health and well-being of CMC and their families (e.g., suitability of home environment to child's medical technology, understanding of complex medication or care regimen). Examining which domains of SDOH and psychosocial adversity are most impactful on CMC and family well-being can help to refine and adapt psychosocial screening for CMC and their families.

The short- and long-term impact of a year (or more) of service disruption on the developmental, physical health, and behavioral health of CMC remains unknown. Therefore, ongoing screening and health surveillance for these families is imperative in identifying and addressing the longer-term implications of the COVID-19 pandemic on health and well-being. Moreover, national data demonstrates that communities of color were disproportionately impacted by the COVID-19 pandemic (Center for Disease Control & Prevention, 2021); therefore, evaluation of health disparities experienced by families of color is needed to better understand the impact on child and family well-being during the COVID-19 pandemic. Addressing these disparities is an essential part of fostering continuity of support for families of color, addressing racism within systems of care, and supporting overall child and family well-being.

Despite the challenges faced both before and during the COVID-19 pandemic, many caregivers of CMC also found sources of strength and resiliency—including making new connections or deepening existing connections with others. Thus, it remains essential to support and help

families identify and strengthen resiliency factors as they encounter the ongoing psychosocial stressors all too common among families of CMC.

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DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions. The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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